

GenE EMR-Genome Enabled Electronic Medical Record for Clinicians and Citizens

A GenE EMR is an EMR that provides **access** to clinical data so Internet based applications such as “**Health Heritage** can:

- **Collect, transfer, and integrate** medical, family, social history, new genomic and biomedical data from EMRs, PHRs, and *other primary data sources at the individual level*
- **Deliver Personalized Decision Support** to providers and individuals at various points of care and to desk tops
- **Improve continuity of care** and efficiency through common **protocol portability and automated communication**
- **Provide Patient Empowerment** by better understanding and control of personal health information & family/social networking.
- **Enable Comparative effectiveness studies** and novel discoveries based on large scale data integration
- *EPIC®'s 2010 release is the first qualified GenE-EMR*

Health Heritage's Principles

- Obtains a limited amount of essential data from the various primary sources-*initial focus family history and cancer risk assessment*
- Understands what the data represent
- Inputs the data into existing or newly developed decision support tools
- Delivers the output in ways that can be understood, stored, and easily shared by consumers and clinicians in trusted way
- Monitors use and impact and constantly improves its performance

Cancers & Syndromes Included in Initial Health Heritage Release

Cancers

- Breast Cancer
- Colon Cancer
- Ovarian Cancer
- Endometrial
- Prostate Cancer
- Melanoma
- Stomach Cancer
- Thyroid Cancer
- Pancreatic Cancer
- Renal Cell Cancer
- Lung

Syndromes that Cross Cancers

- Hereditary Breast and Ovarian Cancer Syndrome
- Cowdens Syndrome
- Li-Fraumeni Syndrome
- HNPCC / Lynch
- Wilms Tumor
- Von Hippel Lindau Syndrome
- Familial Renal Cell Cancer
- Hereditary Prostate Cancer
- Basal Cell Nevus Syndrome

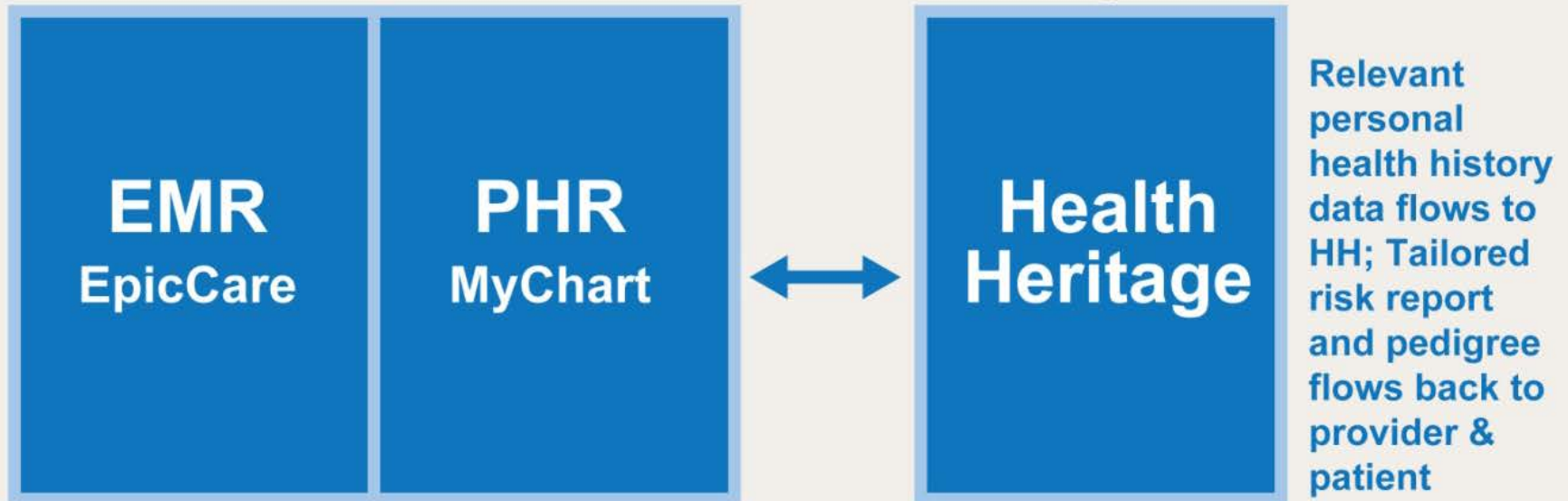
**Supported by The National
Cancer Institute
1RC2CA150911**

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INFORMATION FLOW BETWEEN AN ELECTRONIC MEDICAL RECORD, PERSONAL HEALTH RECORD AND HEALTH HERITAGE

Medical, Surgical, Family History, Labs



Risk Results, Recommendations & Pedigree

System interconnectivity: Single Sign On

- After authenticating into MyChart, patient has the ability to directly access Health Heritage without additional sign on
- Enabled via standard Epic functionality, which allows for a dynamic link with encrypted patient information





Did you know you can invite relatives to share their health information?

[Inviting relatives to share](#) their health information keeps your health history up to date and accurate automatically.

Family Tree

[+ Invite relative to share](#)

[View as Pedigree Chart](#)

Grandparents

Grandma Perkinson
(paternal grandfather)

Grandma Perkinson
(paternal grandmother)

Papa
(maternal grandfather)

Nana
(maternal grandmother)

Parents

Dick Perkinson
(father)

Wynne Perkinson
(mother)

You & Your Siblings

[+ Add Sibling](#)

Sarah Perkinson
(self)

Children

[+ Add Child](#)

Grandchildren

[+ Add Grandchild](#)

Extended Family

[+ Add Family Member](#)

Barbara
(maternal aunt)

HH provides patients with an opportunity to ask relatives if they want to share data

System interconnectivity: Provider to Health Heritage

- Provider accesses HH from within Hyperspace via a menu / toolbar button in Chart Review or other location
- Button is a link that contains both provider and patient context to send to HH

Data Exchange

- Epic data -> HH
 - Enabled primarily via the use of web services
 - Clinical > Get Active Problem List
 - Clinical > Get Medical History
 - Common > Get Patient Demographics
 - Textual data (path reports etc) obtained via Clarity extracts
 - Use Natural Language Processing
- HH results -> Epic
 - HH creates HL7 message (procedure result) with narrative text containing the HH assessment
 - Message deposited into secure shared folder for medical center interface engine to access and deliver to Epic

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Terminology

1. HH attributes mapped to UMLS / SNOMED concepts
2. Epic's 260K diagnosis master file mapped to SNOMED codes
3. NCBO Bioportal identified all SNOMED "parents" for the 36,700 SNOMED codes in the Epic diagnosis master file
4. Identified 4,700 SNOMED codes that have at least one "parent" concept that represents a HH attribute
5. A web service call to a patient's record includes one of these 4,700 SNOMED codes, than it "sets" the specific HH attribute to "present"

(Diagnosis mapping files and hierarchy paths from Bioportal are stored locally and periodically re-created to reflect terminology updates)

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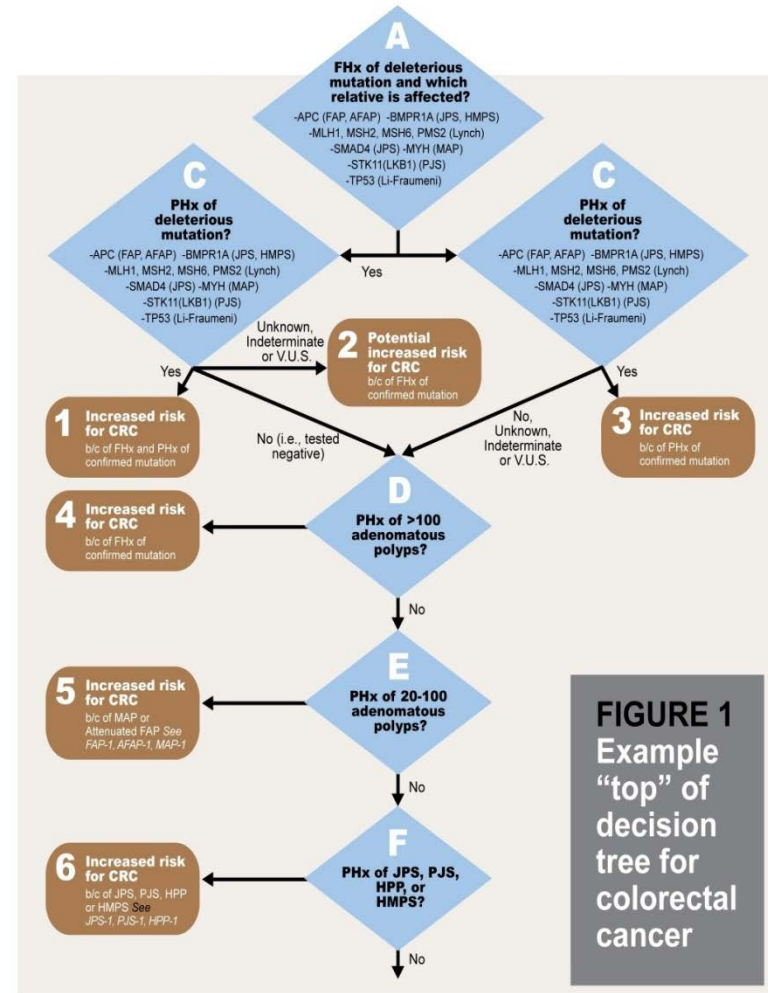
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Evidence Review Process

- Determine all possible risk factors for a cancer
- Iterative search of evidence to access meta-analyses, systematic reviews; guidelines; high quality individual studies
- Use existing guidelines (NCCN) when possible

Developing Decision Support

- Tree structure
 - Risk of carrying a deleterious mutation
 - Other familial risk
 - Clinical diagnoses
 - Cancer-specific risk factors
 - Risk calculators
 - Other factors associated with risk (eg. Lifestyle)

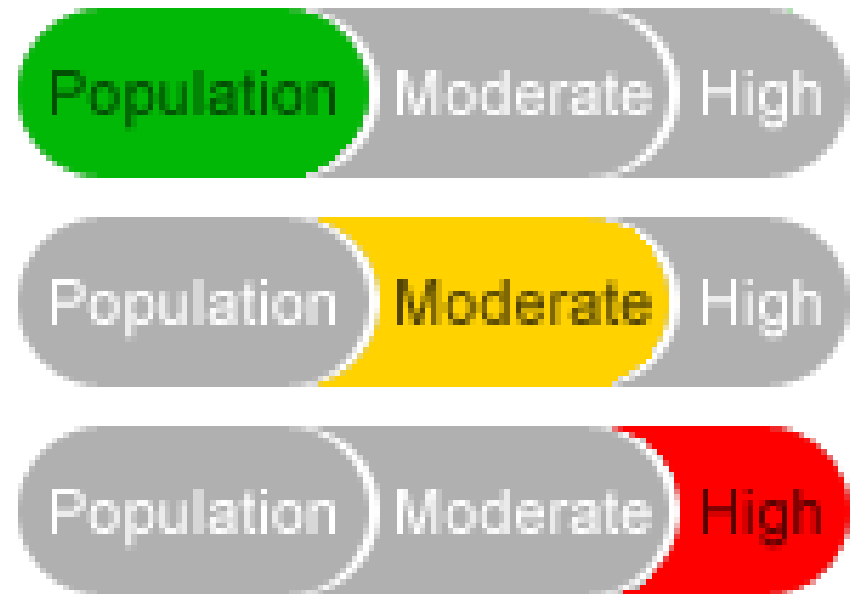


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Risk Levels & Labeling

- Population Risk
 - General population screening messages
- Moderate Risk
 - Evidence-based screening & risk reduction strategies
- Potentially High Risk
 - Genetic Services
- High Risk
 - Genetic Services



Patient-facing report risk level, explanation and “what can I do”

What is my risk for Colorectal Cancer?

Population **Moderate** High

You are at moderate risk for colorectal cancer.

Why am I at risk?

The health information you provided shows that:

- you already have been diagnosed with inflammatory bowel disease (IBD)

Inflammatory bowel disease can cause chronic inflammation of the colon and rectum. It is sometimes called IBD for short. People with inflammatory bowel disease are at higher risk of getting colorectal cancer. Two main types of IBD are ulcerative colitis and Crohn's disease. IBD is more common in people of Jewish heritage. It also tends to run in families: 10 to 25 percent of people with IBD have a first-degree relative (parent, sibling, child) with either Crohn's disease or ulcerative colitis.

What can I do?



This is your Colorectal Cancer Risk Report.

This report was written just for you, but you can click on "Provider" to see the report that was written to your health care provider. Print out either of these reports and show them to your doctor.

Risk Reports

View your risk for:

- M** [Colorectal Cancer](#)
- N R** [Ovarian Cancer](#)
- N R** [Uterine Cancer](#)
- [Prostate Cancer](#)
- [Melanoma](#)

Cautions

This Health Heritage risk assessment is based on the personal and/or family history information that Joe provided.

- If this information is not correct or is incomplete, the recommendation may not be valid
- Having a very small family may limit the strengths of the conclusions
- If the personal and/or family history changes, the recommendation should be reassessed
- New knowledge on Colorectal Cancer risk may arise that changes the risk assessment

Patient **Provider**

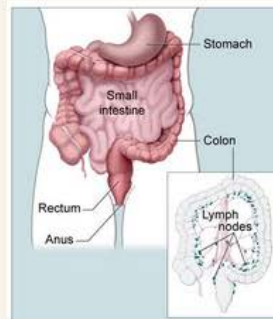
Colorectal Cancer Risk Report

Print this Report

Joe Patient's Health Heritage Full Report / Last Updated 8:03 PM, 7/20/2011

What is Colorectal Cancer?

Colorectal cancer is cancer in the colon or rectum. Sometimes it is called colon cancer for short. The colon is the large intestine and the rectum is the passageway that connects the colon to the anus.



In the United States, colorectal cancer is the fourth most common cancer in men, after skin, prostate, and lung cancer. It is also the fourth most common cancer in women, after skin, breast, and lung cancer.

Although it is quite common, colorectal cancer is one of the easiest to find. When colon cancer does happen, it usually develops slowly. The earlier it is found, the more likely it is to be treatable. There are things you can do to lower your risk of colon cancer or treat it if it does happen. Knowing about your risk can help you and your health care provider make decisions about what to do.

Patient views risk report; has access to provider-facing report

Epic Home Schedule In Basket Encounter Telephone Call OT Editor EpicCare Security Record Viewer GeneEMR

Testlemieux, Chris

Testlemieux, Chris
Male, 76 y.o., 12/01/1934
PCP: None

MRN: 205893
Acct #
None

Allergies
Latex

MyChart: Active
Research: None

LT Isolation: None
Attend Prov: None

Snapshot

Snapshot Well Child Report Specialty Snapshot After Visit Summary

Report: Snapshot

Currently admitted as of 2/19/2011

Demographics

Chris Testlemieux
76 year old male
1234 South Towne Rd
Charlottesville VA 22904
434-683-2120 (H)

Comm Pref:
None

Problem List Chronic

Hospital
Appendicitis
Non-Hospital
Hypertension
HYPERLIPIDEMIA
PERNICIOUS ANEMIA
Colon cancer

Health Maintenance Late Due Soon Hold

None

Reminders and Results

None

Care Team and Communications

PCPs	Type
No PCP set	
Other Patient Care Team Members	Relationship
None	
Recipients of Past Communications	
None	

My Last Outpatient Progress Note

You have written no Outpatient Progress Notes for this patient

Allergies [Mark as Reviewed](#)

LATEX Hives
Last Reviewed by Kjersten Bakke on 11/27/2010 at 1:20 PM: Review Complete

Medications [Show prescriptions](#)

Facility-Administered Medications
No current Facility-Administered Medications

Immunizations/Injections

None

Significant History/Details

None

Specialty Comments [Report](#) [Show All](#) [Edit](#)

No comments regarding your specialty

Family Comments [Edit](#)

None

More Activities

Patient risk report is sent to her doctor's Inbox with a pedigree

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