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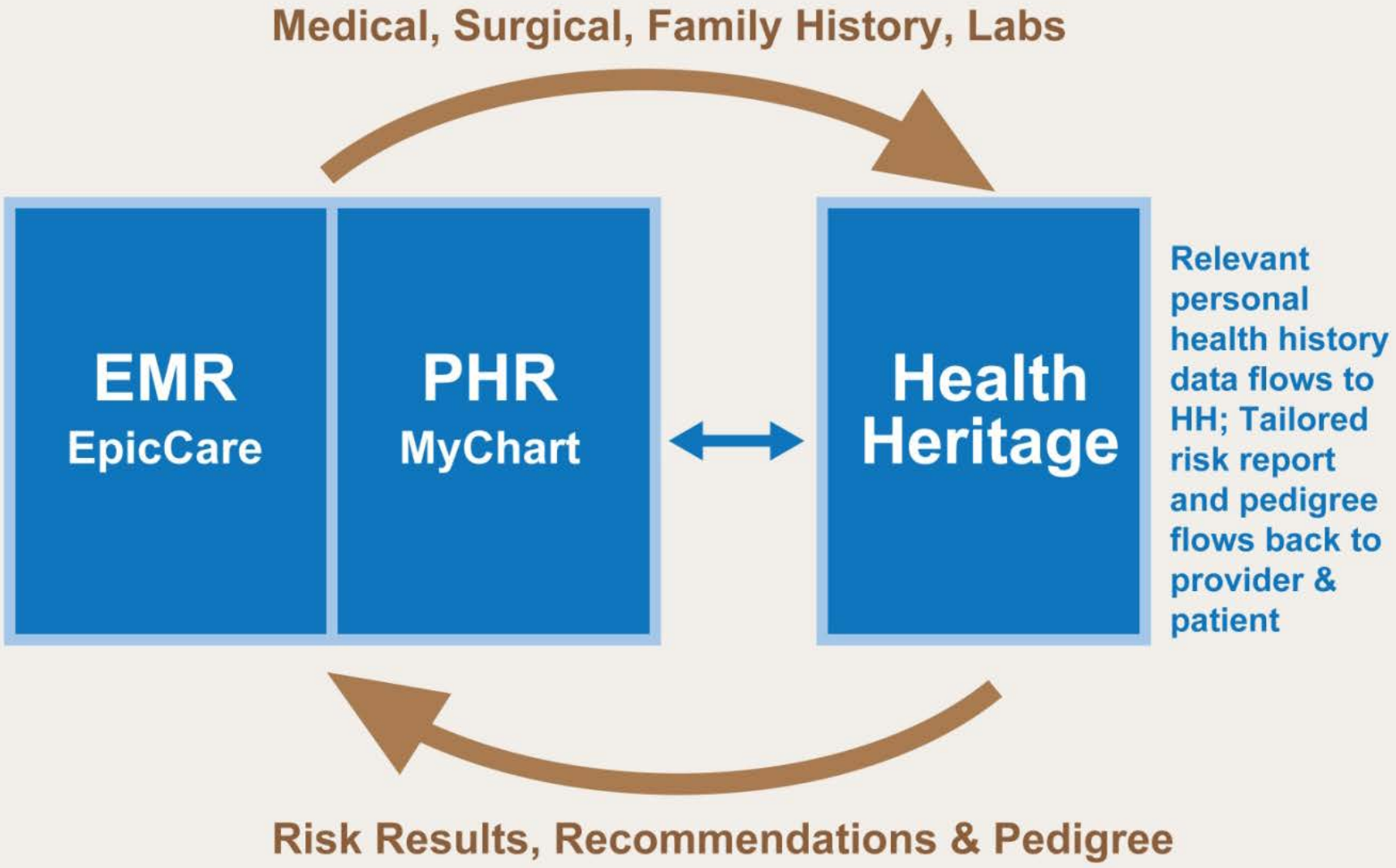
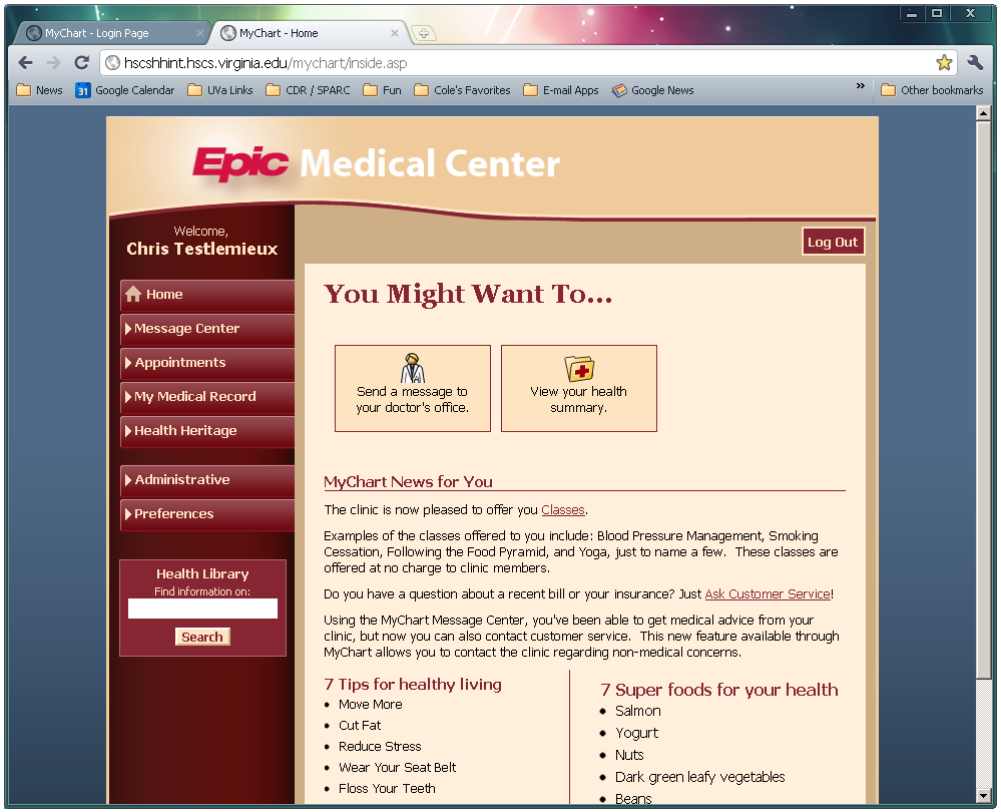
INFORMATION FLOW BETWEEN AN ELECTRONIC MEDICAL RECORD, PERSONAL HEALTH RECORD AND HEALTH HERITAGE

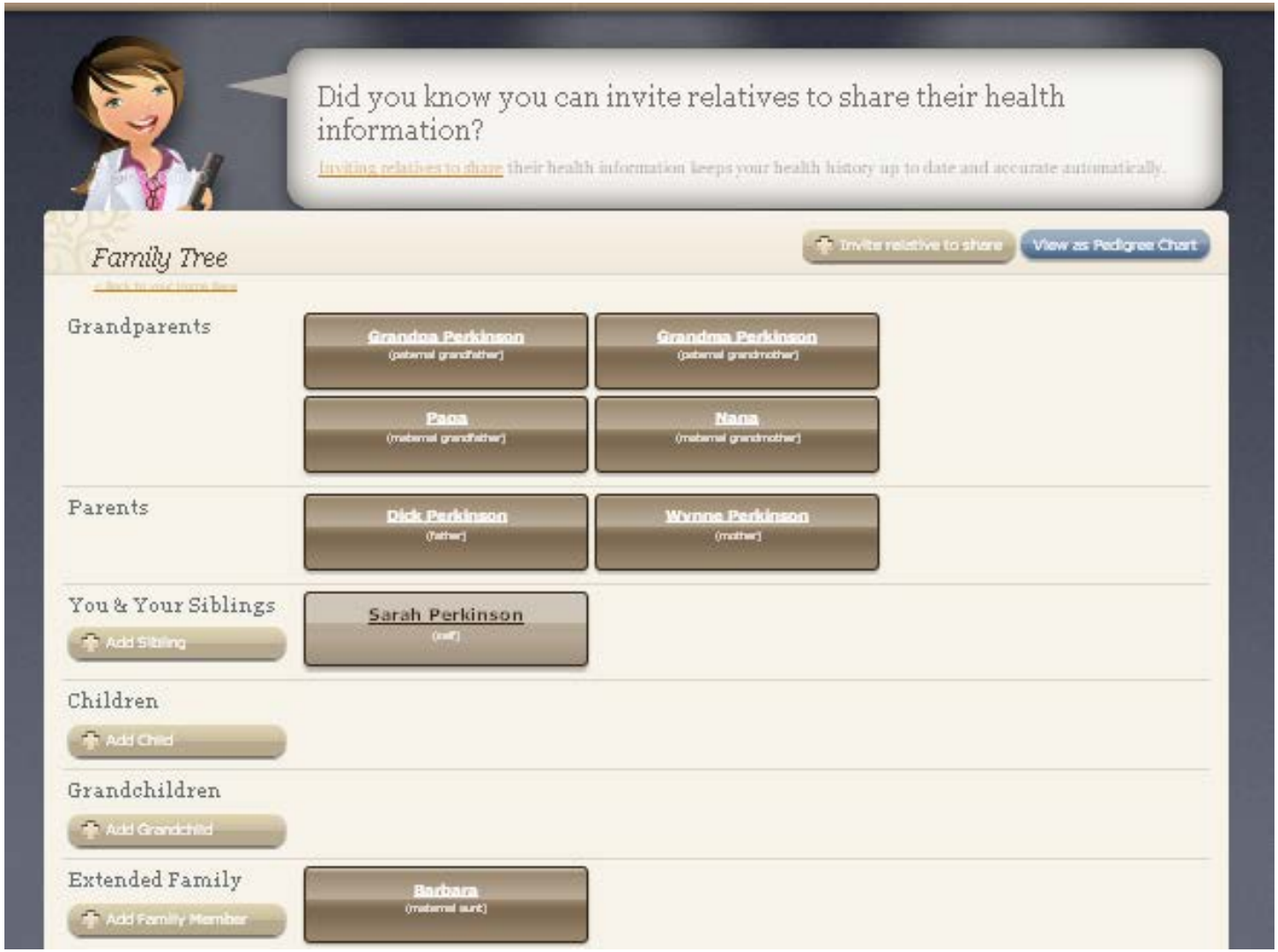


System interconnectivity: Single Sign On

- 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





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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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)

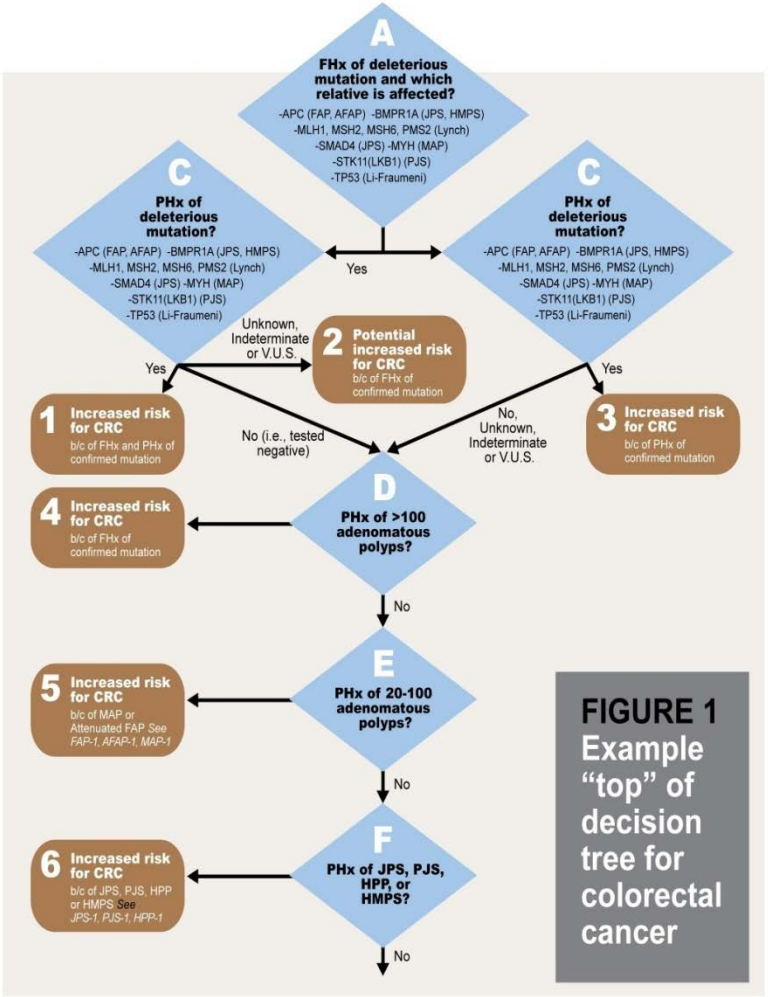

FIGURE 1 Example "top" of decision tree for colorectal cancer

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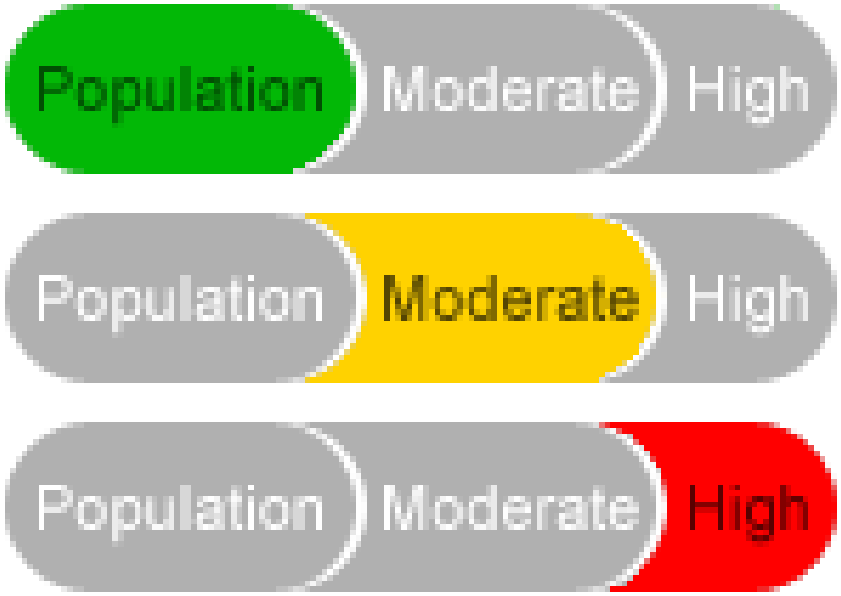
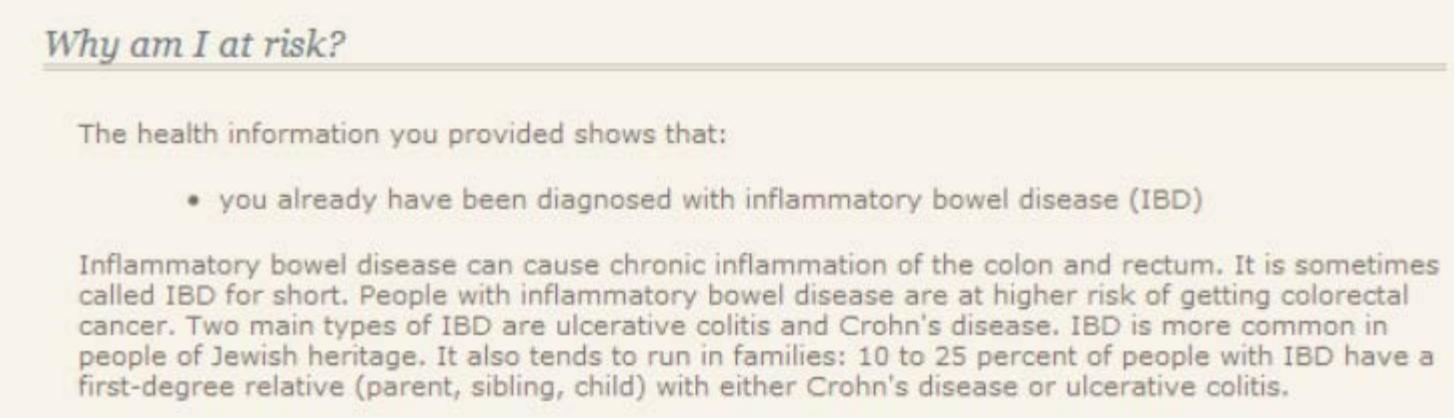
Risk Levels & Labeling

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

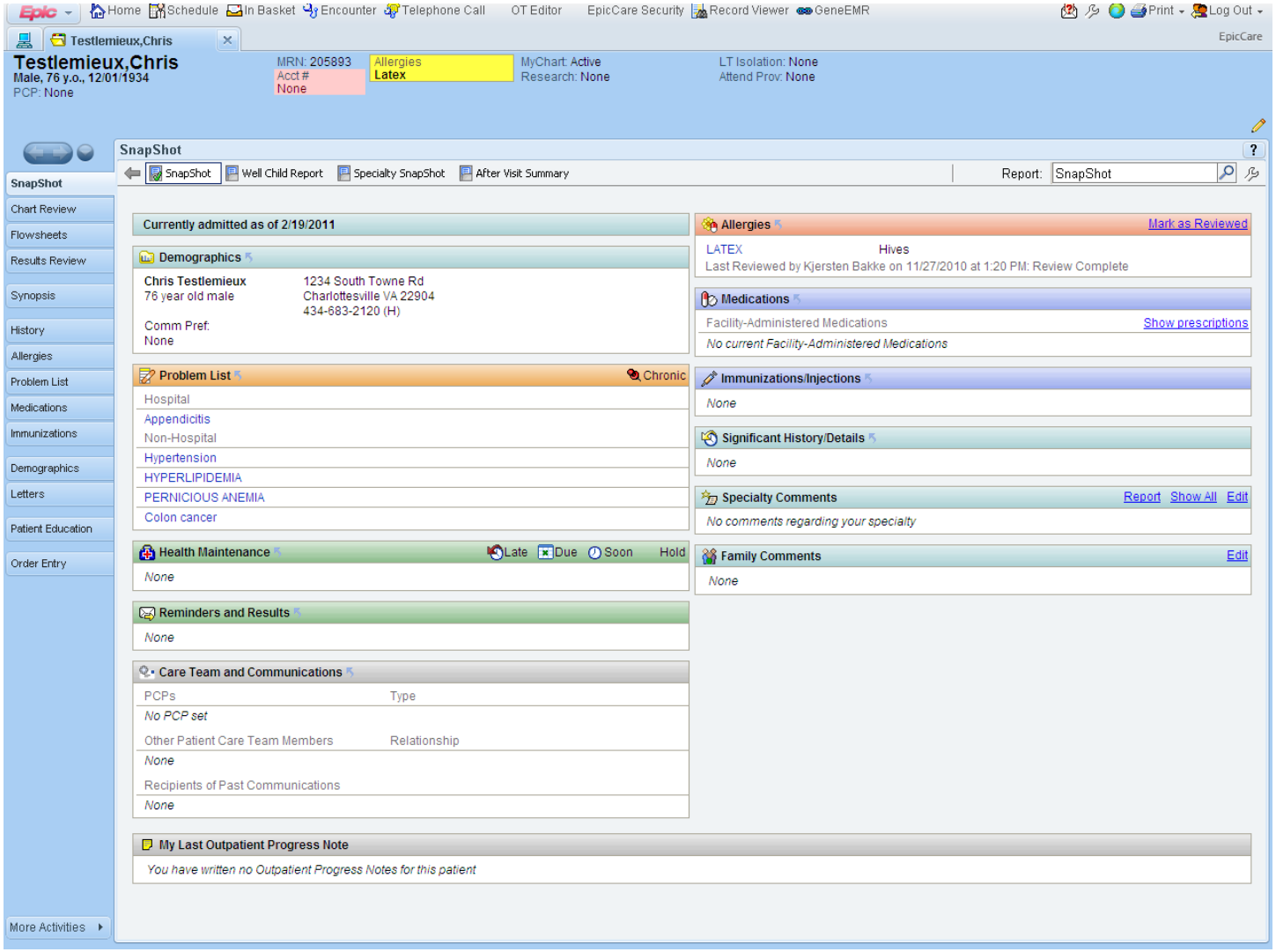


Patient-facing report

risk level, explanation and “what can I do”



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



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

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