NHGRI Activity Update

Greg Feero, M.D., Ph.D.

Sept. 19, 2007

NHGRI Activity Update

1) Personalized Healthcare Workgroup
2) Nursing Tool Box Meeting
3) Posters
4) Top 12 list

Personalized Healthcare Workgroup

Part of American Health Information Community

- Alan Guttmacher, M.D. is on the workgroup
- Greg Feero M.D., Ph.D. is an advisor to the workgroup

Goal (greatly simplified):

To bring some standardization to how EHR systems deal with family history and genetic test information, and to facilitate CDS

HHS Priorities
for America's Health Care

Secretary Leavitt's Priorities

- **Personalized Health Care**
- Medicaid Modernization
- Health Information Technology
- Medicare Rx
- Prevention
- Health Care Value Incentives
- Emergency Response
- Pandemic Preparedness
- New Orleans Health Care System
- Global Health

Secretary's Vision

- **Personalized Health Care:** "Health care is tailored to the individual. Prevention is emphasized. Propensities for disease are identified and addressed through preemptive intervention. Discovery and innovation move drugs to the market and to medical practice faster and at lower cost."
- **The Long Term Objective:** Advances in basic research have positioned us to harness new and increasingly affordable potential in medical and scientific technology. With clinical tools that are increasingly targeted to the individual, our health care system can give consumers and providers the means to make more informed, individualized, and effective choices.
- **The Secretary's 2-year Objective:** Establishes concepts and priorities that support health care system transformation to achieve long term objectives.

American Health Information Community (AHIC)

HHS Priorities for America's Health Care

AHIC is the public-private collaborative that sets priorities and oversees and/or endorses HIT standards, certification, the National Health Information Network, and policies on a national level.

- Supported through the Office of the National Coordinator for Health Information Technology
- Chaired by Secretary Leavitt and Dr. David Brailer
- Seven work groups are now established involving over 100 experts and stakeholders – Biosurveillance, Electronic Health Records, Chronic Care, Consumer Empowerment, Confidentiality, Privacy and Security, Quality, and Personalized Health Care
- Work groups develop recommendations to the AHIC and subsequently to the Secretary for action
  - Example: Executive Order requiring adoption of certification standards for electronic health records

Goals : PHC Initiative

Goal 1: Link Clinical and Genomic Information to Support Personalized Health Care

- Establish an interoperable public/private data partnership of networks to deliver information on individual medical outcomes and linking findings to genetic laboratory test.
- Establish Common Pathway for Data Integration through Electronic Personal Health Records

Goal 2: Support the Appropriate Use of Genetic Information

- Protect individuals from genetic discrimination
- Encourage policies and practices that provide sufficient protections to consumers that genetic test information is used only for their medical benefit
- Provide oversight of genetic testing to assure analytical and clinical validity
- Standardize access policies to federally funded databases of genetic information

AHIC PHC Working Group

HHS Priorities for America's Health Care

John Glaser	Partners HealthCare
Douglas Henley	American Academy of Family Physicians
Carolyn Clancy	Agency for Healthcare Research and Quality
Beryl Crossley	American Clinical Laboratory Association, Quest
Paul Cusenza	23andMe
Andrea Ferreira-Gonzalez	Virginia Commonwealth University
Becky Fisher	Patient Advocate
Felix Frueh	Food and Drug Administration
Emory Fry	Department of Defense
Alan Guttmacher	National Institutes of Health/NHGRI
Kathy Hudson	Genetics and Public Policy Center
Betsy Humphreys	National Institutes of Health/NLM
Charles Kennedy	WellPoint
Joel Kupersmith	Department of Veterans Affairs
Stephen Matteson	Pfizer
Deven McGraw	National Partnership for Women and Families
Amy McGuire	Baylor College of Medicine
Mark Rothstein	University of Louisville
Steve Teutsch	Merck
Janet Warrington	Affymetrix
Andrew Wiesenthal	Permanente Federation
Marc Williams	Intermountain Healthcare

Near Term Priorities

Genetic/Genomic Tests

- Inclusion of relevant genetic/genomic test results in the EHR
- Information to describe analytical validity, clinical validity, and clinical utility of genetic/genomic tests
- Incentives for development and evaluation of new genetic/genomic tests
- Consumer education about the potential benefits and risks associated with genetic/genomic tests
- Harmonization of standards for submission of clinical pharmacogenomics data and state-mandated newborn screens

Near Term Priorities (cont.)

Family Health History

- Consumer and clinician entry of family health history information in the interoperable PHR and EHR
- Support clinician use of consumer entered family health history information
- Standardization of nomenclature for family relationship and other data
- Characterization of the validity and utility of use of family health history in making clinical decisions

Long Term Priorities

Clinical Decision Support

- Development of approaches to informing the clinician of the clinical utility of test results
- Development and assessment of genetics/genomics predictive algorithms
- Development and assessment of genetics/genomics-based CDS to guide treatment and medication dosing decisions
- Incentives for development and incorporation of clinical decision support tools in EHRs

Long Term Priorities (cont.)

Confidentiality, Privacy, and Security

- Technical solutions and policy considerations to ensure that genetic/genomic information will be used appropriately
- Capabilities to link large datasets to generate large-scale, individual-level genetic/genomic data with sufficient protections and limits for use
- Balancing the desires of the research community to have secure and consented access to clinical databases with the privacy and confidentiality rights of the consumer and clinician
- Understanding the risks associated with certain types of genetic/genomic information:
  - Contextual access criteria limits to necessary information
  - Ensuring privacy and confidentiality rules apply to all collection/exchange of health information
  - Research to assess CPS of the NHIN and consumer confidence

PHC Workgroup Next Steps

Short Term

- Two subgroups
  - Genetic/Genomic Tests
  - Family Health History
- Recommendations approved by the AHIC at July 31, 2007 meeting

Longer Term

- PHC-CPS Subgroup
  - Coordinate activities with AHIC Confidentiality, Privacy, and Security Workgroup
- CDS Ad-hoc Workgroup
  - Coordinate activities across AHIC Electronic Health Records, Personalized Health Care, Population Health and Clinical Care Connections, and Quality Workgroups

Recommendation Approved by AHIC July 31, 2007

Recommendation 1.0:

The Community should advance the area of Personalized Health Care as a Priority for Use Case Development.

Recommendation 2.0:

An extension to the Harmonized Use Case for EHRs (Laboratory Results Reporting) should be developed to address the specific information needs in the pre-analytic, analytic, and post-analytic phases of genetic/genomic tests. This extension to the use case should additionally address the need for integrated data flow across the pre-analytic, analytic, and post-analytic phases of genetic/genomic testing and address both the EHR and Laboratory Information Systems.

Recommendation 3.0:

A multi-stakeholder workgroup, including the private sector, federal health care providers, and federal Public Health Service agencies, should be formed to develop a core minimum data set and common data definition available for primary care collection of family health history information.

Recommendations Cont:

Recommendation 3.1:

Additionally, studies should be performed as part of this collaboration as an evidence-base to determine the validity and utility of family health history risk assessment and management tools, clinical decision support tools, and how clinicians view this information as helpful for informing their medical decisions.

Recommendation 3.2:

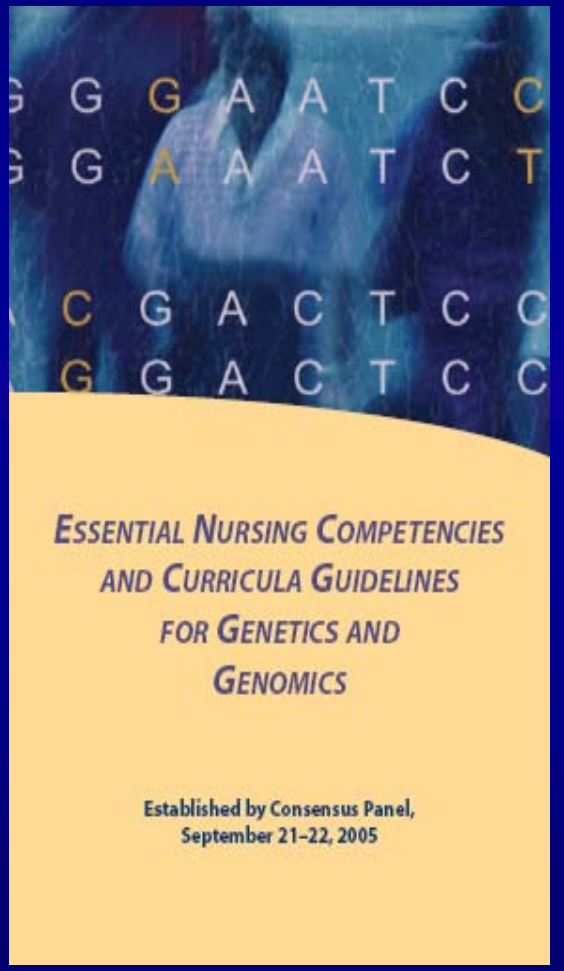
Federal agencies in conjunction with private health care organizations with similar interests and expertise sponsoring pilots in the area of family health history should be used to evaluate the core minimum data set and evidence-base developed through Recommendations 3.0 and 3.1. Health care providers involved in these pilots should also examine the feasibility of consumer-clinician exchange of family health history information between PHR and EHR systems. When possible, the pilots should test and implement the standards and architecture identified in the HITSP developed use case.

Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics

- Meeting held Sept. 2005 to define essential genetic and genomic competencies for all registered nurses - endorsed by 48 professional groups.

Implementation

- Strategic Implementation Plan meeting held October 22-24, 2006
  - Stakeholders from educational institutions, professional associations, certifying bodies and regulatory agencies met to plan for next steps.



Academia: Toolkit for nursing faculty (consider interdisciplinary)

- Meeting held September 14, 2007
- In collaboration with the American Association Colleges of Nursing
- Discussed faculty needs; available resources; gaps; and product options.
- Next steps: finalize what to include, how to package, and funding options.

KEY COMPONENT

- Awareness of relevancy of genetic and genomic information for quality healthcare services
- Consider marketing campaign that includes patient stories

Have you seen Mary…or Fred…or Bob?*

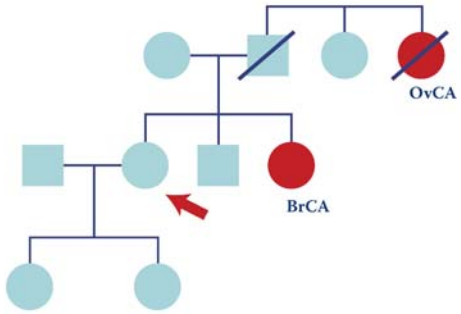
Five poster-format messages targeting PA's, focusing on family history

- Hereditary breast and ovarian cancer syndrome
- Diabetes
- Coronary artery disease
- Hereditary non-polyposis colorectal cancer syndrome
- Preconception care (Tay-Sachs)

*Jane Ades, NHGRI

Caring for Mary in Your Practice

Discovering Hereditary Breast and Ovarian Cancer



Mary is a 38-year old healthy mother of two who likes to jog, doesn't smoke, doesn't drink, watches her diet, and has faithfully gone each year to her primary care provider in her old home town. In short, Mary seems a woman with little risk for serious disease.

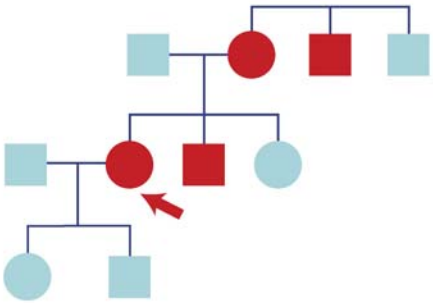
Five years ago, Mary's then 42 year old sister was diagnosed with early stage breast cancer. Fortunately, her cancer was localized and, with treatment, she did well. Unfortunately, Mary's primary care provider never asked Mary about her family history.

This year Mary will move and begin seeing a new primary care provider. Her new provider will take her family history and learn about the cancer in Mary's sister. Additionally, her new provider will discover that Mary's paternal aunt died at age 28 from ovarian cancer, before Mary was born. Mary's new provider will recognize that these facts from her family's medical history put Mary and Mary's family at risk of having hereditary breast and ovarian cancer syndrome. This affects about 1 in 800 individuals and increases the risk of developing certain cancers at a very early age. Mary's new provider will counsel Mary to speak to her sister about seeking additional information about her family's risk. Together Mary and her sister will undergo genetic counseling and learn through genetic testing that they carry a change in the BRCA 1 gene known to cause hereditary breast and ovarian cancer. Each of them will choose slightly different proven health care options that reduce their risk of potentially fatal disease.

YOU are Mary's new primary care provider. Congratulations – **YOU** will quite possibly save Mary's life, and perhaps that of her mother, sister, and children.

U.S. Surgeon General's
Family History Initiative
http://www.hhs.gov/familyhistory

Do You Take That Extra Step Caring for Your Patient?



Vanessa, 35, has just finished walking with her daughter and feels great. These walks are now part of her daily routine, and her healthcare provider tells her she won't need medication for her diabetes in the foreseeable future.

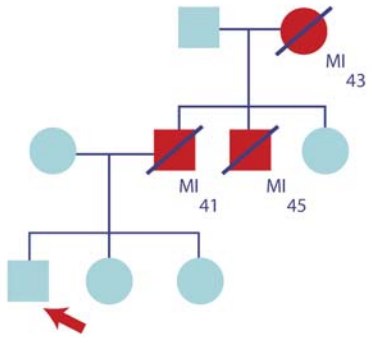
The outlook for Vanessa might not have been this good. All too often diabetes goes undiagnosed for years, with high blood sugars silently affecting vulnerable organs like the eyes, kidneys, and heart. By the time symptoms appear, organ damage has occurred. Luckily for Vanessa, her healthcare provider asked her about her family history at her last physical and found that her mother, uncle, and brother all developed diabetes in their early 40's. This prompted Vanessa's provider to check her fasting blood sugar, which was abnormal. With diet changes and exercise, Vanessa's sugars are in the normal range, and she is helping the rest of her family adopt a healthy lifestyle.

Obtaining your patient's family history can make a real difference to them and their family's health. The U.S. Surgeon General's My Family Health Portrait tool can help your patients to gather and organize their family history before they come to your office.

U.S. Surgeon General's
Family History Initiative
http://www.hhs.gov/familyhistory

Henry, 34, Likes His Morning Coffee

Today Henry can enjoy his coffee feeling confident that there are many more mornings like this one to come. Sadly, Henry's father wasn't so lucky. His life was cut short by a heart attack when he was only 41. As happens with about one in three heart attacks, it came almost without warning. Almost, save a strong family history of heart disease.



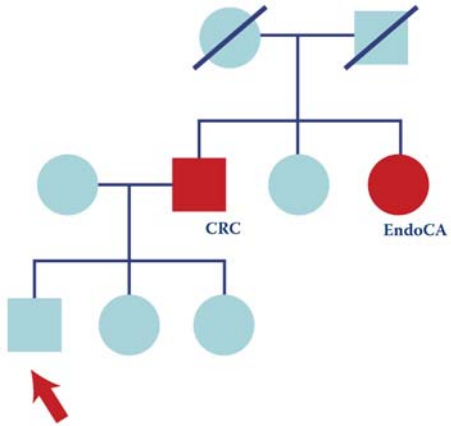
Unlike his father, Henry and his healthcare provider discussed Henry's family history at his last complete physical exam. Henry's healthcare provider learned of the tragedy of Henry's father and as well that Henry's grandmother and uncle both had heart attacks when they were in their early 40's. A quick lab test revealed that Henry's total cholesterol was 300.

As a result, Henry's lifestyle has undergone some recent changes, including a new medication, giving up smoking, and starting a new diet and exercise program. It hasn't been easy. But Henry's not complaining; after all it is a good cup of coffee.

The next time you see Henry, spend some time obtaining a family history, it can make the difference of a lifetime.

U.S. Surgeon General's
Family History Initiative
http://www.hhs.gov/familyhistory

Are YOU John's primary care provider?



Why did John, who is 35, have a colonoscopy?

John and his son bike 5 miles a day. He eats a low fat diet. John has a great job, loves his kids, and next Spring plans to hike the Appalachian Trail. John has one more reason to smile. He had a normal colonoscopy yesterday.

Why was he happy to have a colonoscopy? Because John's primary care provider took a thorough family history at his physical last fall. This history revealed that John's father was diagnosed with colon cancer when he was only 45, and that John's paternal aunt had endometrial cancer at 30. John's primary care provider realized that this put his patient at increased risk for a condition known as hereditary non-polyposis colorectal cancer syndrome (HNPCC), or Lynch syndrome.

This condition causes about 3-5% of all cases of colorectal cancer and greatly increases the risk of early onset colon and endometrial cancer in affected individuals. John's primary care provider referred John to a specialist familiar with this disorder. John and his family underwent genetic counseling and had testing that revealed that John and several of his relatives carry a gene alteration causing HNPCC. Armed with this knowledge, John and the others in his family with this gene alteration now get regular cancer screening beginning at an early age. Early and frequent colon cancer screening for people with HNPCC has been shown to save lives, and it may save John's.

U.S. Surgeon General's
Family History Initiative
http://www.hhs.gov/familyhistory

Baby's First Visit Comes Early

Prenatal Care and Genetics

Jane and Bob are adding on to their home. Why? Because Jane and Bob will soon experience the joy of bringing a healthy newborn girl into their family. Excellent preconception care helped to assure that the health of their baby was not left to chance.

This will be Jane's first child. For this pregnancy Jane chose a new health care provider, who took a thorough family history at a preconception visit. Jane's family history revealed that both she and Bob were of French Canadian ancestry. Jane's provider recognized that this put Jane at elevated risk of having a baby with Tay-Sachs disease, a lethal inherited disorder affecting the nervous system and explained this to Jane and Bob. Jane and Bob chose to have genetic counseling and genetic testing and learned that they were both carriers of gene alterations that could cause Tay-Sachs. Jane and Bob then elected to have prenatal genetic testing to determine if their baby would be affected. To everyone's joy the testing revealed that their baby would not inherit Tay-Sachs.

Are **YOU** the provider helping Jane to bring her new daughter into the world?

To learn more about how genetics is relevant to your practice visit www.genome.gov

HIS FAMILY MEDICAL HISTORY WILL HELP YOU TREAT HIM TODAY. ASK ABOUT IT.

Obtaining a child's family history can help optimize care and treatment; it can also be an important tool for preventive medicine and public health. More accurately identifying children at risk for conditions including diabetes, cardiovascular disease, and single gene disorders such as cystic fibrosis and fragile X syndrome can change the primary care clinician's approach to pediatric medicine. A family history can be used as:

1. A diagnostic tool and guide to testing and evaluation
2. A way to identify patterns of inheritance
3. A patient education tool

To find out more about the importance of family history in pediatric care, please click here.

Additional resources:
CDC's Pediatric Genetics Information
CDC's Family History Resources & Tools
U.S. Surgeon General's My Family Health Portrait

CDC

Mary con't.

- Content?
- Format?
- Venues?
- Target audience?
- Other topics
  - Broad (e.g. pharmacogenomics)
  - Specific (e.g. other family history topics)

Top 12 Topics For PA Education In Genetics

1. Hereditary Cancer Syndromes
   a. breast cancer genetics
   b. colorectal cancer genetics
2. Cancer Genetics
3. Lifestage Genetics
   a. Pregnancy & the perinatal period
   b. Infancy
   c. Childhood and adolescence
   d. Adulthood
4. Family Pedigree History
5. Genetic Counseling & Making a Genetics Referral
6. Genetics of common disease
7. Genetic Testing
8. Pharmacogenomics
9. Thrombophilias
10. Psychiatric genetics
11. Nutrigenetics
12. Basic Concepts in Genetic Science

Top 12 topics for PA education in genetics

How do we move forward with these topics

- Who are the targets?
  - Educators
  - Students
  - PA's in practice
- What venue?
  - Courses?
  - Publications?
  - Web-based?
- Who will populate list?
  - Geneticists
  - Other specialists
  - PA's?

GENETIC TOOLS: Building a Model Curriculum for Family Medicine Residency Education

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[4]*Medical History and Ethics, University of Washington, Seattle, WA*

Developed in part by funds from the Maternal and Child Health Bureau, Health Resources and Services Administration

Background & Purpose: Genetics Education in Family Medicine

Most Family Medicine residencies do not formally incorporate genetics into the curriculum. Genetics topics are addressed as they arise in clinical practice.

A number of educational resources for genetics education in primary care are freely available on the Internet. However, little guidance exists to assist primary-care faculty in making use of available resources in teaching. In particular, strategies are lacking for the opportunistic integration of this material into the existing curriculum.

Key requirements for the curriculum were to:
(1) Develop a modular approach to ensure flexibility for different topics and teaching formats,
(2) Ensure peer review by teaching faculty,
(3) Account for relevant ACGME and RRC requirements for Family Medicine, and
(4) Ensure ease of access, downloads, and updates.

The Model Curriculum Working Group

The Model Curriculum Working Group was established in November 2005 to develop strategies to help faculty integrate existing tools for genetics teaching into local curricula. The Working Group convened twice to:

(1) Review existing online resources,
(2) Review applicable ACGME and RRC requirements, and
(3) Develop strategies for incorporating genetics into the existing Family Medicine curriculum.

Tools identified for use:
GeneticTools, www.genetictools.org
GeneTests, www.genetests.org
AAFP CME unit, www.aafp.org/online/en/home/clinical/acf/genomics/acfgenomics.html

Thanks to the members of the Model Curriculum Working Group: Susie B
Feero, MD, PhD, Maine-Dartmouth Family Practice Residency Program, K
Washington, Valerie Ross, MS, University of Washington, Kerry Silvey, MA, Children's Development & Rehabilitation Center, Oregon Health & Science University, Nancy Stevens, MD, MPH, University of Washington, Michael Stehney, MD, MPH, Middlesex Hospital, Susan Brown Trinidad, MA, University of Washington, Adam Wilikofsky, PhD, Lancaster General Hospital, Calanthe Wilson-Pant, MD, McLaughlin Research Institute

Suggested Teaching Approaches Template

Suggested Teaching Approaches were developed for autism/developmental delay; Alzheimer disease/dementia; breast and ovarian cancer; colorectal cancer; hereditary hemochromatosis; family history; newborn screening; and pharmacogenomics.

With this modular approach, faculty can select the most appropriate tools and teaching points, whether they have 5 minutes at the bedside or a full hour-long didactic presentation. Suggestions for self-directed learning are also offered. Relevant ACGME/RRC competencies are identified.

Suggested Teaching Approaches: Hereditary Colorectal Cancer

Format 1: Point of Care	(~ 5 minutes) Also available: Suggested teaching approaches for Morning Report (~20 min), Noon Conference/Didactic Session (~60 min), and Self-Directed Learning
Setting & approach—where and how will this information be used by faculty?	These suggestions are intended to help faculty be prepared for questions that come up in clinical teaching, and to respond to learners' requests for additional information
Suggested pre-reading for faculty and/or discussion leaders	At-A-Glance topic on colorectal cancer, www.genetictools.org Suggested sites: www.ccalliance.org; http://ghr.nl,.nih.gov, www.genereviews.org, UpToDate, MDConsult Suggested search terms: FAP, hereditary colorectal cancer, HNPCC
Suggested mini-topics	***Medical Knowledge*** What percentage of CRC cases may be hereditary? What are "red flags" suggesting the possibility of an inherited CRC syndrome? What are the three major entities of inherited CRC? Compare and contrast HNPCC and FAP. Discuss evaluation options for suspected cases. Discuss screening options/recommendations for those at increased risk for CRC, and implications for other family members. Discuss prophylaxis/treatment options for those identified as having HNPCC or FAP ***Interpersonal & Communication Skills*** How might one integrate a discussion of hereditary cancer risk into a routine health maintenace visit? How might one best elicit a patient's concerns regardng a family history of colon cancer? ***Professionalism & Ethical, Legal, Social, and Cultural Implications*** What is the role (obligation?) of the physician to family members that may be at risk for hereditary CRC? What are the potential economic and social impacts of the diagnosis of HNPCC or FAP on the patient?
Suggested additional reading/information for learners	At-A-Glance topic on colorectal cancer, www.genetictools.org GeneticTools case 8: a woman unaware of her family history of colorectal cancer GeneticTools case 9: colorectal cancer in a 28-year-old woman NCI's Genetics of Colorectal Cancer PDQ: www.nci.nih.gov/cancertopics/pdq/genetics/colorectal/healthprofessional
Outcome—main teaching points or desired behavior change	Increased recognition of the contribution of hereditary factors to the burden of CRC Improved understanding of the evaluation and management of patients at risk for, or having, hereditary CRC Recognition that significant economic, ethical, and psychosocial issues surround a diagnosis of a hereditary CRC syndrome

Format 1: Point of Care (~ 5 min)	
Setting and approach Where and how will this information be used by faculty?	These suggestions are intended to help faculty be prepared for questions that come up in clinical teaching, and to respond to learners' requests for additional information.
Suggested pre-reading for faculty and/or discussion leaders Resources and/or references you would recommend to help faculty/discussion leaders feel comfortable with this topic	▸ At-A-Glance topic on Colorectal Cancer, www.genetictools.org ▪**Suggested Sites:** o www.ccalliance.org o http://ghr.nlm.nih.gov o www.genereviews.org o UptoDate o MDConsult ▸ **Suggested search terms: FAP, hereditary colorectal cancer, HNPCC**
Suggested mini-topics Small "chunks" of information that address questions that commonly arise in clinical precepting and point-of-care teaching. Preceptors and other faculty should be able to quickly scan these topics, then choose an appropriate mini-topic or two (based on current cases, residents' questions, or faculty interest) to incorporate in teaching.	***Medical Knowledge*** ▸ What percentage of CRC cases may be hereditary? ▸ What are "red flags" suggesting the possibility of an inherited CRC syndrome? ▸ What are the three major entities of inherited CRC? ▸ Compare and contrast HNPCC and FAP. ▸ Discuss evaluation options for suspected cases. ▸ Discuss screening options/recommendations for those at increased risk for CRC, and implications for family members. ▸ Discuss prophylaxis/treatment options for those identified as having HNPCC or FAP. ***Interpersonal & Communication Skills*** ▸ How might one best integrate a discussion of hereditary cancer risk into a routine health maintenance visit? ▸ How might one best elicit a patient's concerns regarding a family history of colon cancer? ***Professionalism & ELSI*** ▸ What is the role (obligation?) of the the physician to family members that may be at risk for hereditary CRC? ▸ What are the potential economic and social impacts of the diagnosis of HNPCC or FAP on the patient?
Suggested additional reading/information for learners Resources and/or references you would recommend for those who want to learn more about this topic	▸ At-A-Glance topic on Colorectal Cancer , www.genetictools.org ▪GeneticTools case 8, a year-old woman unaware of her family history of colorectal cancer, http://www.genetests.org/servlet/access?id=8888892&key=4ogu0lp2Lwiio&fcn=y&fw=CZHV&filename=/tools/cases/colorectal-8/index.html ▸ GeneticTools case 9, Colorectal cancer in a 28-year-old woman, http://www.genetests.org/servlet/access?id=8888892&key=4ogu0lp2Lwiio&fcn=y&fw=sZ0B&filename=/tools/cases/colorectal-9/index.html ▸ National Cancer Institute's "Genetics of Colorecetal Cancer PDQ," http://www.nci.nih.gov/cancertopics/pdq/genetics/colorectal/healthprofessional
Outcome What are the main teaching points or desired behavior changes to be addressed?	▸ Increased recognition of the contribution of hereditary factors to the burden of CRC. ▸ An improved understanding of the evaluation and management of patients at risk for or having hereditary CRC. ▸ Recognition that significant economic, ethical, and psychosocial issues surround a diagnosis of a hereditary CRC syndrome.

Format 2: Morning Report (~ 20 min.)	
Setting and approach Where and how will this information be used by faculty?	Brief informal discussion of case-based materials presenting major points regarding Hereditary Colorectal Cancer. Could be led by faculty or chief/senior resident. Advance preparation is expected.
Suggested pre-reading for faculty and/or discussion leaders Resources and/or references you would recommend to help faculty/discussion leaders feel comfortable with this topic	▸ At-A-Glance topic on Colorectal Cancer, www.genetictools.org ▸ GeneticTools case 8, a year-old woman unaware of her family history of colorectal cancer, http://www.genetests.org/servlet/access?id=8888892&key=4ogu0lp2Lwiio&fcn=y&fw=CZHV&filename=/tools/cases/colorectal-8/index.html ▸ GeneticTools case 9, Colorectal cancer in a 28-year-old woman, http://www.genetests.org/servlet/access?id=8888892&key=4ogu0lp2Lwiio&fcn=y&fw=sZ0B&filename=/tools/cases/colorectal-9/index.html
Suggested approaches Your suggestions for how to teach this material in the Morning Report setting, within the available time, and offering developmentally appropriate learning opportunities for both junior and senior house staff.	***Approach 1: Build on Mini-Topics*** ▸ Some of the 5-minute mini-topics suggested for Point of Care teaching (above) can be expanded, modified, or combined to work in a 20-minute teaching discussion. Add a 1 or 2-sentence case at the start to introduce the topic, and spend more time asking questions and discussing each point. ***Approach 2: Case Presentation*** On appropriate inpatient teaching service (Family Practice, Internal Medicine, Surgery) with morning report or teaching rounds, select a patient with CRC for presentation. Assign a team member to briefly present the case (3–5 minutes). Assign team pre-reading and set the date for case presentation. Direct discussion towards the issues selected from above Mini-Topics.
Suggested discussion topics/questions Your suggestions for guiding discussion of key issues about the topic and/or case.	***Medical Knowledge*** ▸ What percentage of CRC cases may be hereditary? ▸ What are “red flags” suggesting the possibility of an inherited CRC syndrome? ▸ What are the three major entities of inherited CRC? ▸ Compare and contrast HNPCC and FAP. ▸ Discuss evaluation options for suspected cases. ▸ Discuss screening options/recommendations for those at increased risk for CRC, and implications for family members. ▸ Discuss prophylaxis/treatment options for those identified as having HNPCC or FAP. ***Interpersonal & Communication Skills*** ▸ How might one best integrate a discussion of hereditary cancer risk into a routine health maintenance visit? ▸ How might one best elicit a patient’s concerns regarding a family history of colon cancer? ▸ What is his/her reaction to, and comprehension of, the material surrounding hereditary CRC? ▸ How might further evaluation and genetic testing be helpful? Harmful? ***Professionalism & ELSI*** ▸ What is the role (obligation?) of the the physician to family members that may be at risk for hereditary CRC? ▸ What are the potential economic and social impacts of the diagnosis of HNPCC or FAP on the patient?

Format 3: Noon Conference / Didactic Session (~ 1 hour)	
Setting and approach Where and how will this information be used by faculty?	This section helps faculty prepare a formal lecture-style presentation of information on Colorectal Cancer, in a Noon Conference or other didactic classroom-style setting. Suggestions for faculty pre-reading, as well as learner preparation, are offered.
Suggested pre-reading for faculty and/or discussion leaders Resources and/or references you would recommend to help faculty/discussion leaders feel comfortable with this topic	Audience: ▸ At-A-Glance topic on Colorectal Cancer, www.genetictools.org Presenter: ▸ National Cancer Institute's "Genetics of Colorecetal Cancer PDQ," http://www.nci.nih.gov/cancertopics/pdq/genetics/colorectal/healthprofessional
Suggested approaches Your suggestions for how to teach this material in the Noon Conference / Didactic setting, within the available time	Select a noon conference slot every 3 years for this topic. Assign faculty with interest in colorectal cancer to review slide sets and update if needed. Selected faculty will need to be familiar with the topic in order to effectively present and field questions. Limit presentation to 45 minutes, allowing 15 minutes for discussion of questions and/or cases of interest. (See below for suggested discussion topics/questions)
Suggested classroom materials If you know of teaching tools (eg, handouts, slide sets, websites) that can be used effectively in this setting, please note them here.	▸ At-A-Glance topic on Colorectal Cancer, www.genetictools.org, as handout ▸ Slide sets available from CDC genetic educational materials web site (e.g., those posted by the University of North Carolina). This may require permission (which this Working Group should obtain) and updating/tailoring to audience. http://www.sph.unc.edu/nccgph/tools/colon_cancer2_files/frame.htm ▸ AAFP Annual Clinical Focus Colorectal Cancer video module (***Note:*** requires high-speed Internet access), http://www.aafp.org/x30164.xml
Suggested discussion topics/questions Your suggestions for guiding discussion of key issues about the topic and/or case	***Medical Knowledge*** ▸ What percentage of CRC cases may be hereditary? ▸ What are "red flags" suggesting the possibility of an inherited CRC syndrome? ▸ What are the three major entities of inherited CRC? ▸ Compare and contrast HNPCC and FAP. ▸ Discuss evaluation options for suspected cases. ▸ Discuss screening options/recommendations for those at increased risk for CRC, and implications for family members. ▸ Discuss prophylaxis/treatment options for those identified as having HNPCC or FAP. ***Interpersonal & Communication Skills*** ▸ How might one best integrate a discussion of hereditary cancer risk into a routine health maintenance visit? ▸ How might one best elicit a patient's concerns regarding a family history of colon cancer? ▸ What is his/her reaction to, and comprehension of, the material surrounding hereditary CRC? ▸ How might further evaluation and genetic testing be helpful? Harmful? ***Professionalism & ELSI*** ▸ What is the role (obligation?) of the the physician to family members that may be at risk for hereditary CRC? ▸ What are the potential economic and social impacts of the diagnosis of HNPCC or FAP on the patient?

http://edoctoring.ncl.ac.uk/System_Check/

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Welcome to the eDoctoring website.

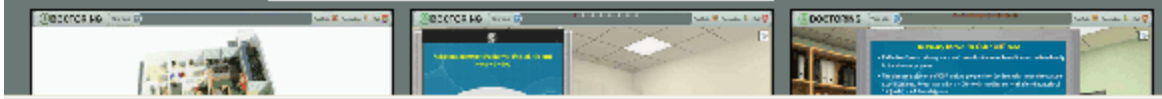
The project is a collaboration between the Newcastle University and the University of California. Its aim is to provide an online support tool for the Doctoring curriculum through the use of highly interactive case based material.

Requires login **Request Login**
You need to download flash 8 to use eDoctoring **Click here to install plug-in**

News

- New end of life cases are being developed and deployed within the system,
- New graphics for the whole site have been applied,
- New content delivery system applied to allow the multiple eDoctoring systems to operate in a new hospital based enviornment,
- New 3D graphics applied to the prostate / genetics cases, including new animated office interactions,
- Multiple genetics cases available online,
- Take a peek at some early eDoctoring screenshots in the **'Gallery'**.

Screenshots View more screenshots in the gallery



Internet | 100%

e-Doctoring screenshots from March 2007 - release version. Comments from Dan Plummer, programmer.

The eDoctoring system uses a portfolio to monitor your progress through the cases.

On your first login to the system you are given a virtual tour of the enviroment.

Patients / Cases are assigned according to your course and cover a wide variety of material from Genetics to Screen tests.

eDoctoring uses videos to help visualise the cases.

The cases are narrated by professor agents and use graphical displays to emphasise points in the learning material.

To make the material more interactive, questions are used through out to test your knowledge.

At the end of each case, a summary screen highlights the important points made about the patient and condition.

Some of the more important aspects of the cases are supported by seperate tutorials that provide more in-depth material.

[Older Screenshots]

Top 12 topics for PA education in genetics

Approaches:

- PDA support (GeneFacts - NCHPEG)
- Virtual clinic tool (NCHPEG, eDoctoring, Dartmouth)
- Article series (Rocky and others)
- Video CME (AAFP ACF)

Conclusions

- NHGRI is currently engaged in a variety of activities that will affect PA practice
- Key points for collaboration include awareness campaigns and development of educational resources
- Opportunities exist for inter-disciplinary synergy in these key areas