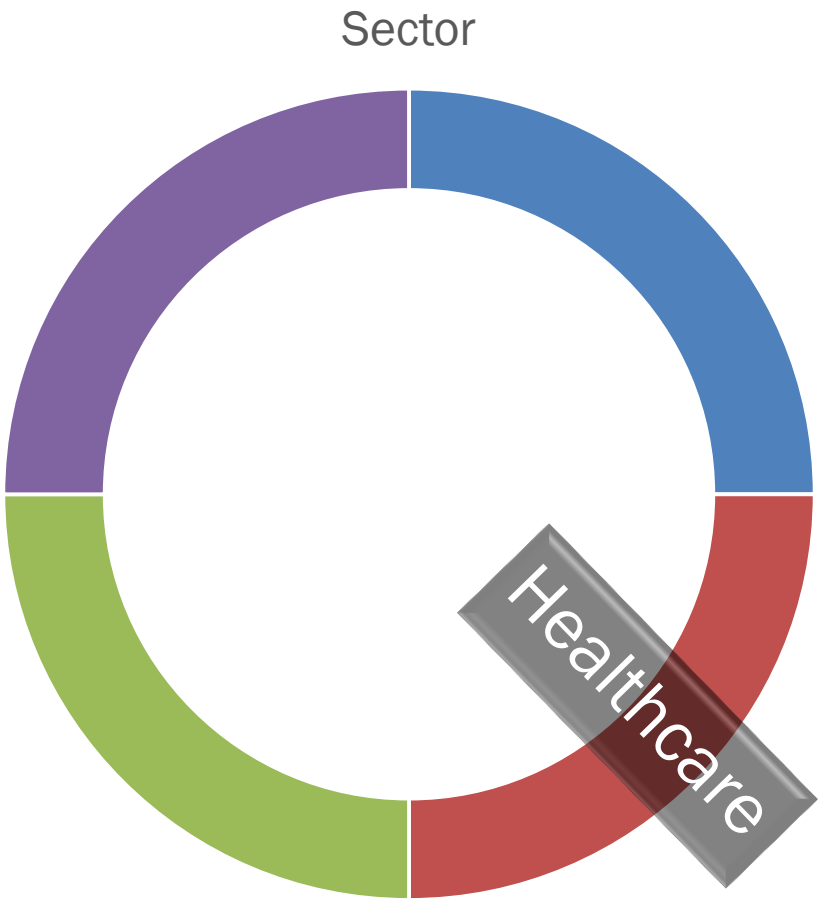
Education Tools and Programs from the Genomic Healthcare Branch

Bob Wildin, M.D.
Chief, Genomic Healthcare Branch
Division of Policy, Communications, and Education

National Human Genome Research Institute

GHB Focus



GHB Methods

- Assess

Initiate

Catalyze

Targets

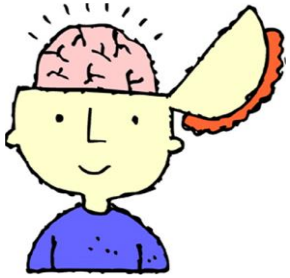
GHB Mission

- Promote the effective integration of genomic discoveries into healthcare

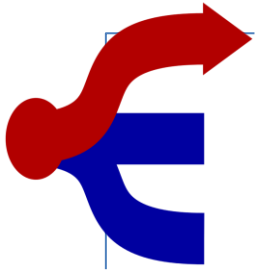
- Informing research needs in application and implementation research at the NHGRI and beyond
- **Promoting the development and evaluation of tools that enable healthcare providers to take more effective advantage of advances in genomics**
- **Promoting genetics literacy among the full spectrum of healthcare providers and their patients**
- Serving as a liaison between the healthcare community and the NHGRI, and encouraging dialogue with healthcare providers and organizations with an interest in the role of emerging genomic technologies in reshaping healthcare.

Promoting genomic literacy

Language and Images



Knowledge



Disambiguation

Familiarity

For Providers

Provider Tools

- Genetics and Genomics Competency Center (http://g-2-c-2.org)
- Global Genetics and Genomics Community (http://g-3-c.org)

Provider Education

- NHGRI Website, “Health Pages” (http://genome.gov/health)
- Inter-Society Coordinating Committee (ISCC, http://genome.gov/iscc)
- NHGRI Summer Short Course (http://genome.gov/shortcourse/healthprofessionals)
- Insurer Webinar Series (https://www.genome.gov/27563343)
- Nursing Education: MINC Toolkit, Nursing Research Platform, others
- Myriad videos, lectures, patient care resources, and other education resources

GENETICS / GENOMICS COMPETENCY CENTER

Home | Competency Map | Saved Resources | Meet the Experts

Getting Started with G2C2

Use G2C2 to search for Genetics & Genomics Resources for use in Your Classroom or Practice

Find websites, books, articles and more - enhance your class content with peer-reviewed resources.

Search the Genetics/Genomics Competency Center

Text Search | Search By Discipline | Search By Topic

Enter Search Term or Phrase

Search

Search Competencies

Match your classroom genetics/genomics searching to competencies.

View Saved Resources

As you find resources, you can save them and send to yourself or others by email.

Submit a Resource

Do you have activities, resources or assessments you would like to share?

G2C2

G3C


Global Genetics and Genomics Community
Home
Resources
About
Login / Register
GENOMIC HEALTH CARE SIMULATIONS
Interview "patients" at your own pace
Complete supplemental educational activities
Assess your genomic competency
Consider commentary about specific cases from genomic experts
Earn CNE or CME credit for each case
YOU ASK THE QUESTIONS
Recognize the indications for predisposition genetic testing for a known deleterious mutation in a
HOW IT WORKS
1
Login or Register
Join the G3C Learning Portal for free and expand your genetic/genomic knowledge.
2
Choose from 15 Cases
Narrow your search based on topic and level of difficulty.
3
Start Seeing Patients
Apply what you learn today. Lead your "patients" to quality healthcare outcomes.
Unfolding Case Studies for Genetics & Genomics Healthcare Education
Register

Research Funding | Research at NHGRI | Health | Education | Issues in Genetics | Newsroom | Careers & Training | About | Español

Health

Information about genetics and genomics, rare diseases, patient care and more

For Patients and the Public

- Community Engagement and Community Health
- Family History
- Genetics & Genomics Science & Research
- Genetic & Rare Diseases Information Center
- Genomic Medicine and Health Care
- Online Health and Support Resources
- Specific Genetic Disorders

For Health Care Providers

- Competency & Curricular Resources
- Genetics 101
- Genomic Medicine and Health Care
- Inter-Society Coordinating Committee (ISCC)
- New Horizons and Research
- Patient Management
- Policy and Ethics Issues

Genome.gov/Health

Feature

NIH awards $55 million to build million-person precision medicine study

Bethesda, Md., Thurs., July 7, 2016 - **The U.S. Food and Drug Administration (FDA)** has announced two draft guidances to support President Obama's Precision Medicine Initiative. The guidances will help provide oversight for tests based on next generation sequencing, a technology that examines a person's DNA to detect medically important differences in genomic make-up that could increase the risk for disease. **Read more**

The NIH Family Health History Tool Conference

On June 14 and 15, 2016, NHGRI held the **NIH Family Health History Tool Conference,** also sponsored by the Genomic Healthcare Branch (GHB) and the Division of Policy, Communications, and Education (DPCE). The overarching goal is "To prepare the FHHT field to improve personal health by responding effectively to rapid changes in Family Health History (FHH) data uses, Health Information Technology (HIT) capabilities, and research opportunities." **Read more**

Highlights

Video: *A G2C2 Website Overview*

This introduction to the Genetics/Genomics Competency Center (G2C2) website at http://g-2-c-2.org/, gives new users an opportunity to view key features of this centralized collection of genomics educational resources for healthcare educators and providers. **Read more**

Genomic knowledge is power in the fight against obesity

Although many doctors are wary about discussing weight loss with their overweight patients - for fear of alienating the patients or being ignored - two recent research studies from a team led by NHGRI's Susan Persky, Ph.D., suggest that doctor-patient talks about the genomic underpinnings of obesity can pay off. **Read more**

Genomics in Medicine Lecture Series

YouTube **The Genomics in Medicine Lecture Series Videos (25 Videos)**

Last Updated: July 7, 2016

See Also

- GenomeTV
- Genomic Healthcare Branch
- Fact Sheets
- Genetic Education Resources for Teachers
- All About the Human Genome Project
- Health Archive

On Other Sites:

YouTube GenomeTV
NHGRI's YouTube channel

- Office of Rare Diseases Research (ORDR)
- ClinicalTrials.gov
- Pediatric Genetics

En Español:

- Recursos del Instituto Nacional de Investigación del Genoma Humano y los Institutos Nacionales de la Salud (NIH) en Español
- Glosario El Hablar De Términos Genéticos
  Nuestro glosario de los multimedia con las ilustraciones downloadable.

En Otro Sitio: Centro de Información sobre Enfermedades Genéticas y Raras

Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC)

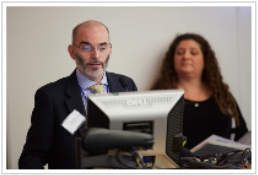
Overview

The Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC) formed in February 2013 from the Genomic Medicine IV meeting to improve genomic literacy of physicians and other practitioners and to enhance the practice of genomic medicine through sharing of educational approaches and joint identification of educational needs. The group facilitates interactions among medical professional societies and the NIH Institutes & Centers to exchange practices and resources in genomic education and clinical care. By identifying needs of societies and clinicians in filling in gaps in evidence and knowledge and in providing effective educational efforts, the ISCC offers partnership and available expertise to these societies to guide development of educational initiatives and applications for clinically relevant advances in genomic science. Incremental evolution in identification of relevant sequence variation will permit gradual expansion of practitioners' knowledge and practice in applying genomics to clinical care.

For more information on the ISCC and its mission, refer to the following ISCC Description

Members

The ISCC brings together representatives from medical professional societies, NIH Institutes & Centers (ICs), and the NHGRI Genomic Medicine Working Group. The ISCC is co-chaired by an NIH official and an external member.



Co-Chairs

Ann Karty, M.D. (American Academy of Family Physicians)
Bob Wildin, M.D. (National Human Genome Research Institute)

Members and Federal Agency Partners

Accreditation Council for Continuing Medical Education (ACCME)
Accreditation Council for Graduate Medical Education (ACGME)
American Academy of Family Physicians (AAFP)
American Academy of Ophthalmology (AAO)
American Academy of Pediatrics (AAP)
American Association for Clinical Chemistry (AACC)
American Association for Dental Research (AADR)
American Board of Family Medicine (ABFM)
American Board of Medical Genetics (ABMG)
American Board of Medical Specialties (ABMS)
American Board of Ophthalmology (AAO)
American College of Cardiology (ACC)
American College of Medical Genetics and Genomics (ACMG)
American College of Physicians (ACP)
American Congress of Obstetricians and Gynecologists (ACOG)

ISCC

Working Groups

- Case Studies
- Competencies
- Educational Products
- Engagement of Specialty Boards
- Innovative Approaches
- Insurer Staff Education
- Speaking Genetics

Short Course

National Human Genome Research Institute

The Genomic Healthcare Branch within the National Human Genome Research Institute (NHGRI) is offering the NHGRI Short Course in Genomics: Nurse, Physician Assistant and Faculty Track from August 1 - August 3, 2016.

This year's course is for nurses, nurse practitioners, physician assistants and the faculty who educate these health professionals. Participants will be selected who demonstrate an active interest in understanding genomics and genetic testing, integrating genomics into practice, and educating others in genomics within either an academic or clinical setting.

Short Course Flyer PDF

Short Course Agenda

NHGRI Short Course in Genomics: Nurse, Physician Assistant and Faculty Track

Webinars for Health Insurers and Payers: Understanding Genetic Testing

To address the growing need for medical staff in the insurance industry to understand genetic testing, the National Human Genome Research Institute (NHGRI) has collaborated with the Blue Cross Blue Shield Association to produce this educational webinar series. The goal is to prepare insurers to understand genetic testing strategies, interpretations, outcomes and patient care, and use that understanding in making sound decisions regarding the healthcare activities of their insured.

Starting in June 2015, twelve monthly live webinars were produced by volunteer experts in genetic and genomic medicine and testing. Each session was recorded by the association and is now made publicly available at no cost here.

This effort arose from NHGRI's Insurer Education Working Group of the Inter-Society Coordinating Committee for Provider Education (ISCC), beginning in early 2015.

YouTube Video Playlist

Presentations

June 18, 2015

Understanding the Fundamentals: The Language of Genetics
Presenter: Bob Wildin, M.D.
National Human Genome Research Institute, NIH

YouTube Video | Transcript | Slides

The presentation begins with a case study of a 6-year-old boy, "Roger", struggling in class and presenting with short stature. Next, Dr. Wildin reviews basic genetic terminology, including genes/gene structure, genotype, phenotype, penetrance, expressivity, inheritance, variation, mutation types, and how genes are linked to disease. With an understanding of basic genetic principles, participants are asked specific questions about the case. Dr. Wildin reviews answers that lead to a diagnosis for "Roger" that has implications for his family members.

July 14, 2015

Genetic Testing: Who and Why?
Presenter: Kaylene Ready, M.S. C.G.C.
Director, Inherited Cancer at Counsyl

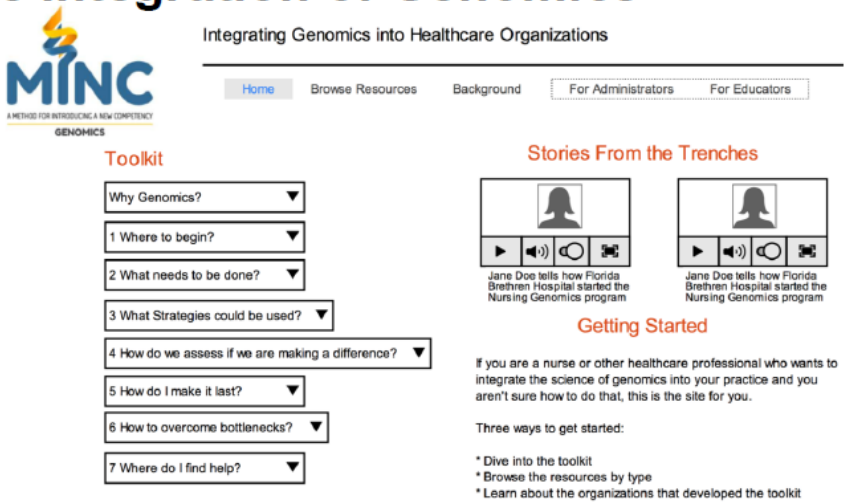
YouTube Video | Transcript | Slides

Different types of genetic tests are described in this webinar, including tests for symptomatic and asymptomatic individuals, tests of an individual's germline to benefit family, and tests of DNA from cancer cells. Goals of genetic testing are presented, including the use of testing for clinical versus molecular diagnosis, as well as principles of clinical utility.

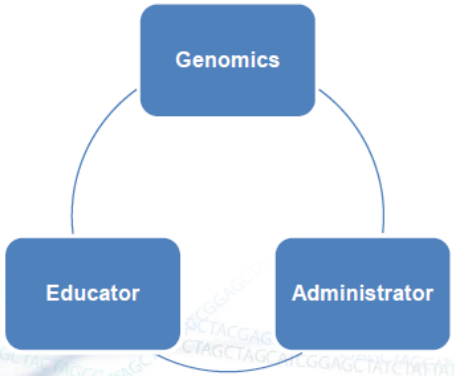
GHB

Insurer Webinars

Toolkit to Facilitate Integration of Genomics



- Promote genomic practice
- Capture dyad expertise and processes
- Collect resources



NIH National Human Genome Research Institute

Division of Policy, Communications, and Education

MINC

GenomeTV

Home › Newsroom › GenomeTV

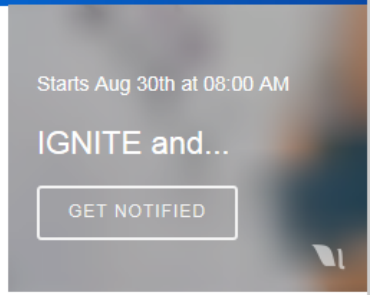
GenomeTV

Search GenomeTV

Welcome

GenomeTV is the National Human Genome Research Institute (NHGRI) collection of video resources. A wide variety of videos is available, from lectures, to news documentaries, to full video collections of meetings that tackle the research, issues and clinical applications of genomic research.

View All Videos



Go to: GenomeTV Live page

Note: Click on the title for the video, on the icon for more information.

NHGRI Advisory Council

- 05/2016 Council Open Session
- 02/2016 Council Open Session
- 09/2015 Council Open Session
- 05/2015 Council Open Session
- 02/2015 Council Open Session

View All

Symposia

- 05/2015 TCGA Fourth Annual Symposium
- 08/2014 GCTP Alumni Research Symposium
- 05/2014 TCGA Third Annual Symposium
- 09/2013 The African Diaspora
- 04/2013 HGP10 Symposium

View All

News and Documentary

- 02/2016 Virtual physician counsels participant
- 11/2015 Family Health History Day
- 09/2015 1000 Genomes Project
- 09/2015 Impact of HGP, 25 Years From Launch
- 09/2015 G2C2 Overview

View All

Lectures

- 06/2016 Genomics and Health Disparities
- 05/2016 Current Topics in Genome Analysis
- 05/2016 Jeffrey M. Trent Lecture
- 04/2016 Harry Potter & Genomics of Wizarding
- 06/2014 Genomics in Medicine (All Videos)

View All

Education and Training

- 08/2015 NHGRI Three-minute Talks (TmT)
- 08/2015 Genetics and Genomics Primer
- 07/2015 (Factor) Analyze This: PCA or EFA
- 03/2015 Pre-Application Webinar: PA-14-015
- 03/2015 Genome: Unlocking Life's Code

View All

Workshops and Meetings

- 06/2016 Investigational Device Exemptions ...
- 06/2016 A Quarter Century After the HGP ...
- 04/2016 Genomic Medicine Meeting IX
- 03/2016 UDN and Beyond Workshop
- 11/2015 NSIGHT Public Webinar

View All

Broadcast Media

Digital files prepared by NHGRI's Communications Branch for use by broadcast media to assist with the preparation of news stories. All are in the public domain and copyright free.

View Broadcast Media

Archived Videos

Videos for events recorded prior to June 13, 2007. Some videos are on YouTube, but most are on the National Institutes of Health video website, *NIH VideoCasting and Podcasting*.

View NHGRI Video Archive

For the Public

•Public Tools

- My Family Health Portrait, the SG's Family History Tool
  (MFHP, http://familyhistory.hhs.gov)

Public Information

- NHGRI Website, "Health Pages"
  (http://genome.gov/health)
- Genetics and Rare Diseases Resource
  (http://rarediseases.info.nih.gov)

Get Help

My Family Health Portrait

A tool from the Surgeon General

Language English

Using My Family Health Portrait you can:

- Enter your family health history.
- Learn about your risk for conditions that can run in families.
- Print your family health history to share with family or your health care provider.
- Save your family health history so you can update it over time.

Talking with your health care provider about your family health history can help you stay healthy!

Learn more about My Family Health Portrait

Create a Family Health History

Use a Saved History

Glossary | FAQ | Accessibility | Privacy | About | Contact | Site Updates

GHB

MFHP

MFHP Landing Page

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Language English

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Learn more about My Family Health Portrait

Create a Family Health History

Use a Saved History

Delete all Data and Restart | Save Family History for Later Re-use | Add Another Family Member | View Diagram and Table

Name	Relationship to me:	Add History	Update History	Remove Relative
My Family				
Robert Wildin	Self			
Robert E. Wildin	Father			

U.S. Department of Health & Human Services | National Institutes of Health | NCATS | Recursos en español

FAQ | Contact GARD

NIH National Center for Advancing Translational Sciences | GARD Genetic and Rare Diseases Information Center

Search

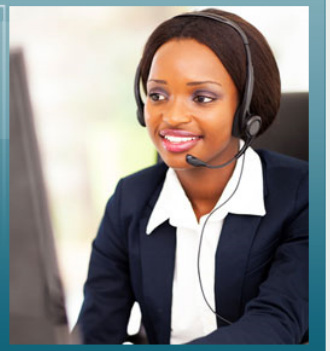
Diseases | Resources | Research | News & Events | About GARD

Have Questions About Genetic or Rare Diseases?

Get reliable answers from the Genetic and Rare Diseases (GARD) Information Center. If you...

Read more...

1 2 3 4



Genetic and Rare Diseases (GARD) Information Center

Search for a condition | Go

Enfermedades en español

Browse Diseases

A B C D E F G H I J K L M

N O P Q R S T U V W X Y Z

0-9

View:

Diseases by Category

Rare Diseases with FDA-Approved Medical Products

About GARD

The Genetic and Rare Diseases (GARD) Information Center is a program of the National Center for Advancing Translational Sciences and is funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). The GARD Information Center provides the public with access to current, reliable, and easy-to-understand information about rare or genetic diseases in English or Spanish.

Read more about GARD.

Your Questions Answered

Answers to recently asked questions from the public on these rare and/or genetic diseases:

- Marden-Walker syndrome
- Eagle syndrome
- Fox-Fordyce disease
- Osteopetrosis
- Brody myopathy

Research

NIH Rare Disease Programs
A select list of NIH-supported research efforts.

- Rare Diseases Clinical Research Network (RDCRN)
- NIH/NCATS GRDR℠ Program (Global Rare Diseases Patient Registry Data Repository)
- Therapeutics for Rare and Neglected Diseases (TRND)
- Undiagnosed Diseases Network (UDN)
- Bench-to-Bedside Awards

Research Funding Resources
Funding opportunities from the NIH and other sources

Tools for Researchers
Resources to aid in research efforts

Get Involved in Research
Learn about research studies, clinical trials, and patient registries

Resources

Featured Guide

How to Find a Disease Specialist

MORE GUIDES

Rare Diseases Resources
A collection of resources for the rare disease community

Genetics Resources
A collection of resources that provide information on genes, genomics, and genetic conditions

Genetic Testing and Treatment
Learn about genetic testing and finding healthcare services

Support for Patients and Families
Organizations that can help you find support and assistance

Teaching Resources
A collection of resources for educators about rare diseases and genetic concepts

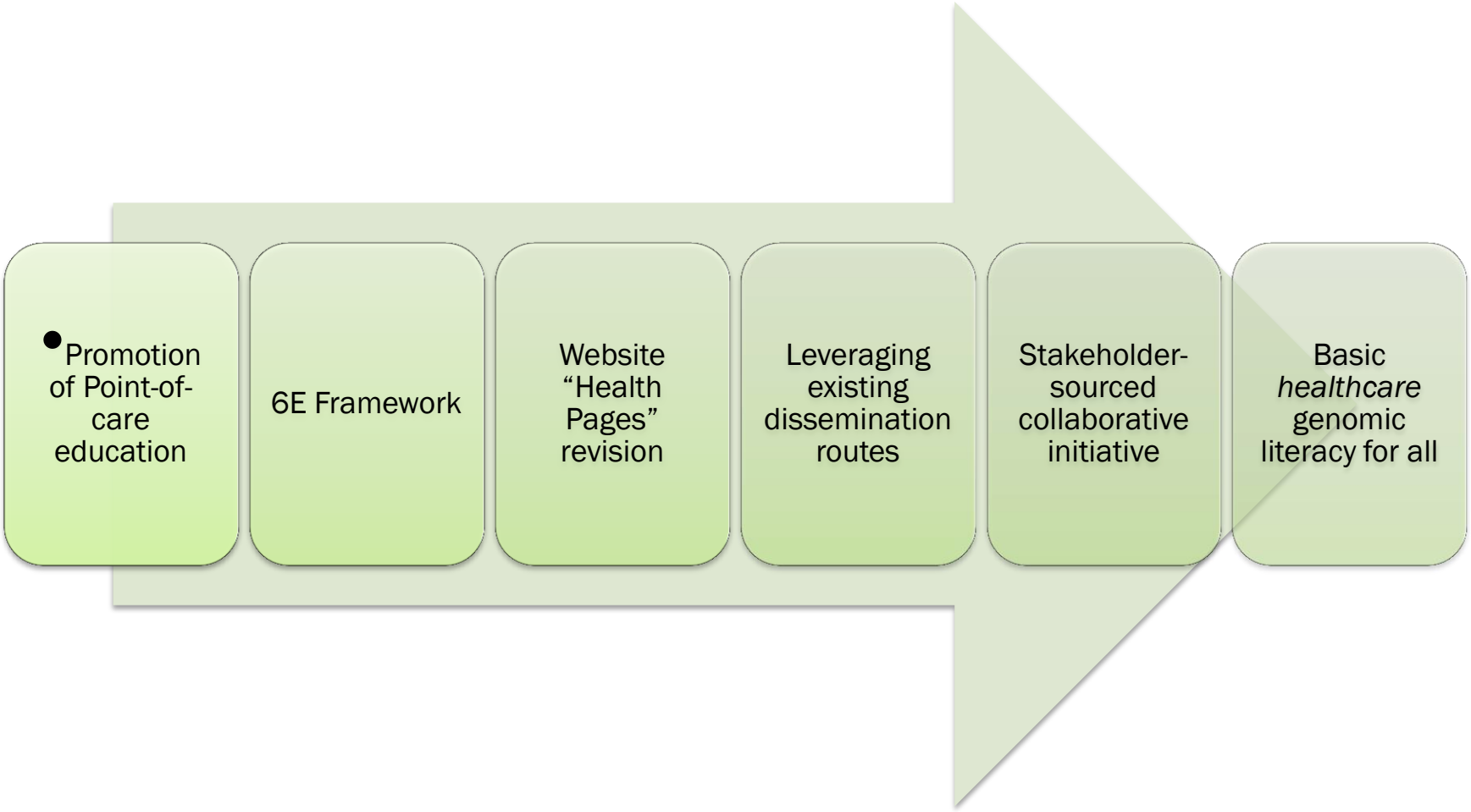
GHB

GARD

Coordination with and monitoring Implementation Research Programs

- Extramural Research Consortia
  - IGNITE
  - eMERGE
  - CSER
  - ClinGen
  - CEER
  - UDN
- Intramural Research
  - ClinSeq
  - UDP

Under Development



Thank you

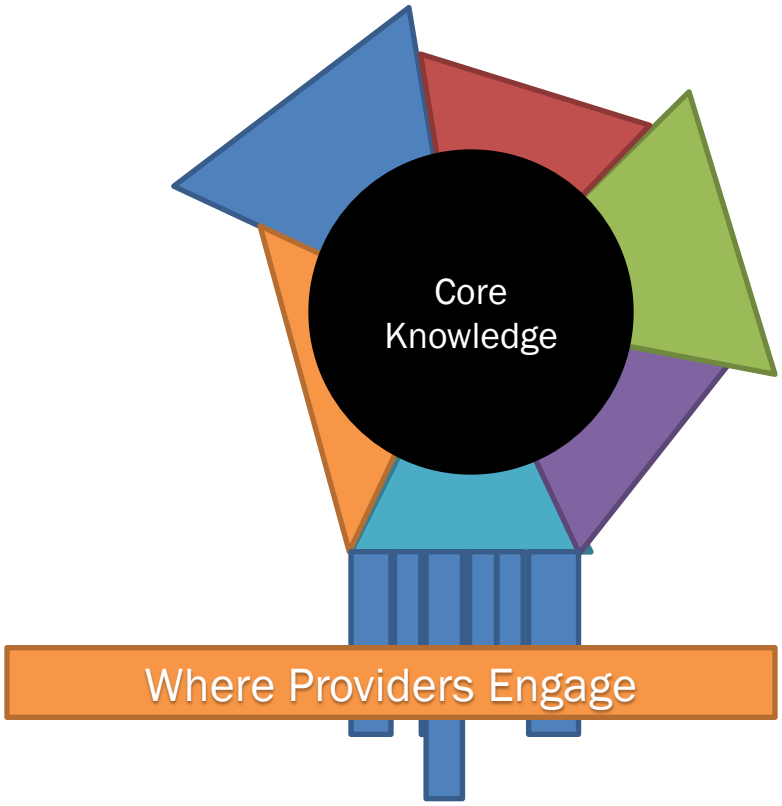
The Bare Essentials of Practitioner Education in Genomic Medicine

Bob Wildin, M.D.

January 23, 2016

National Human Genome Research Institute

The anatomy of Usable Knowledge in Healthcare



Why ‘Bare Essentials’?

- Genomics is discipline- and setting-agnostic, but its clinical use is not
- Rapidly changing knowledgebase
- Relevance to practice is the critical motivator
- Assistive resources are available
- Resources and time for robust education programs are not available

Practitioner Motivations

- Relevance to *their* practice

Effectiveness *compared with* current methods

Time-neutral or better *in their workflows*

- Insurance coverage
- Counseling streamlined
- Data collection streamlined
- Time to learn

Patient satisfaction *as they perceive it*

Cost-neutral or better *as their system perceives it*

Learning Best Practices

Goals of a Universal Provider Education System

- Providers in practice gain knowledge of how to use genomics relevant to *their* practice with minimal effort

Resists obsolescence

A strong education framework that

- is case-based and simple
- is expansible by adding more practice-relevant cases
- is customizable for different specialties
- provides the key education development components *before* customization
- is plug-and-play

Knowledgeable champions contribute cases *without* knowledge of education principles

Evaluates learning success, enables quality metrics

Provides a positive feedback pathway for end user-driven expansion and updating