Genomics-Enabled Learning Health Care Systems: Gathering and Using Genomic Information to Improve Patient Care and Research

SAM SHEKAR MD
GEOFF GINSBURG MD PHD

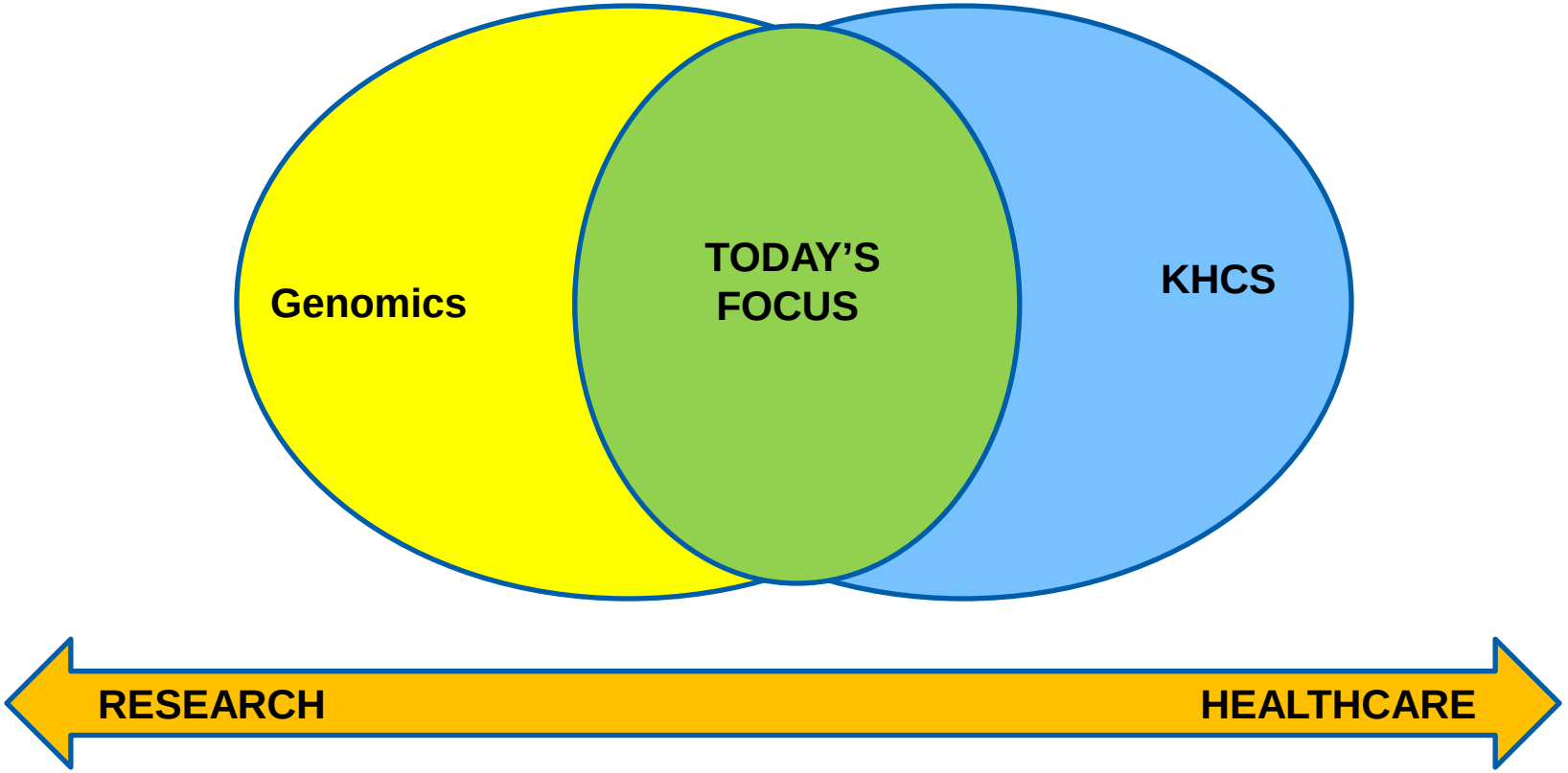
Our Team

- Sarah Beachy
- Adam Berger
- Sam Shekar
- Geoff Ginsburg
- Meredith Hackman
- Jennifer Hall
- Andrew Kasarskis
- Debra Leonard
- James O’Leary
- Erin Payne
- Michelle Penny
- Ron Pryzgodzki
- Mike Watson
- Cathy Wicklund
- Janet Williams

Genomics and Knowledgeable Healthcare Systems

A Simple Guide for Today's Session

NORTHROP GRUMMAN



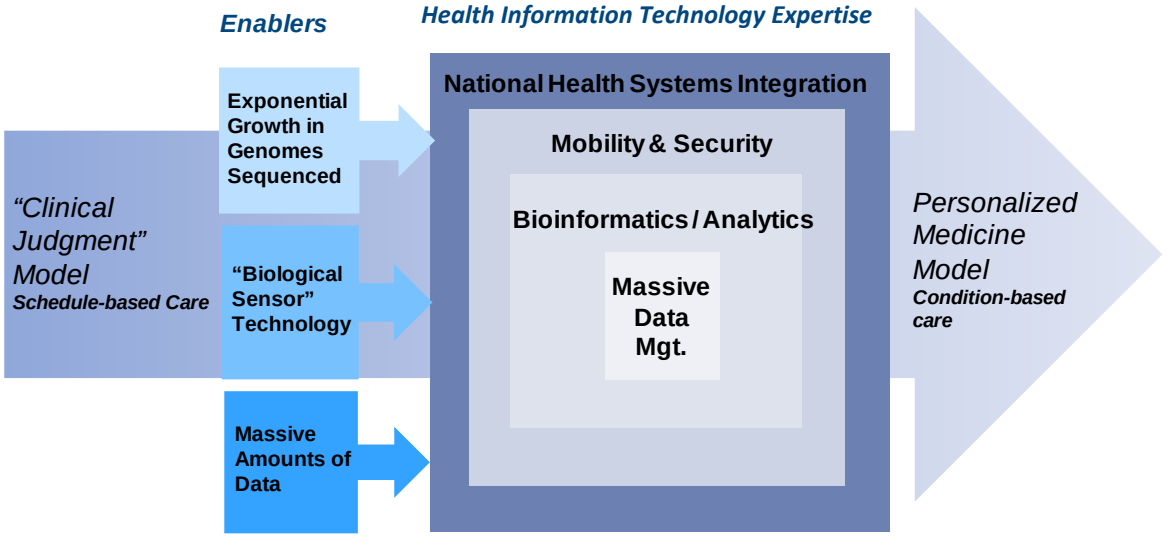
The intersection of Genomics and KHCS presents many challenges and opportunities to advance clinical research and improve patient care

Personalized Healthcare (PHC) and the Role of Health IT

The Next Major Transformation of Health and Healthcare

NORTHROP GRUMMAN

- **What is it?**
  - Using individual genetic information to prevent, diagnose, and treat disease with better precision
- **Why is this a paradigm shift?**
  - Shifts from the current medical model based on clinical judgment to one based on genome-guided care
  - Shifts from a reactive, symptom-based approach to a predictive, preventive and proactive approach



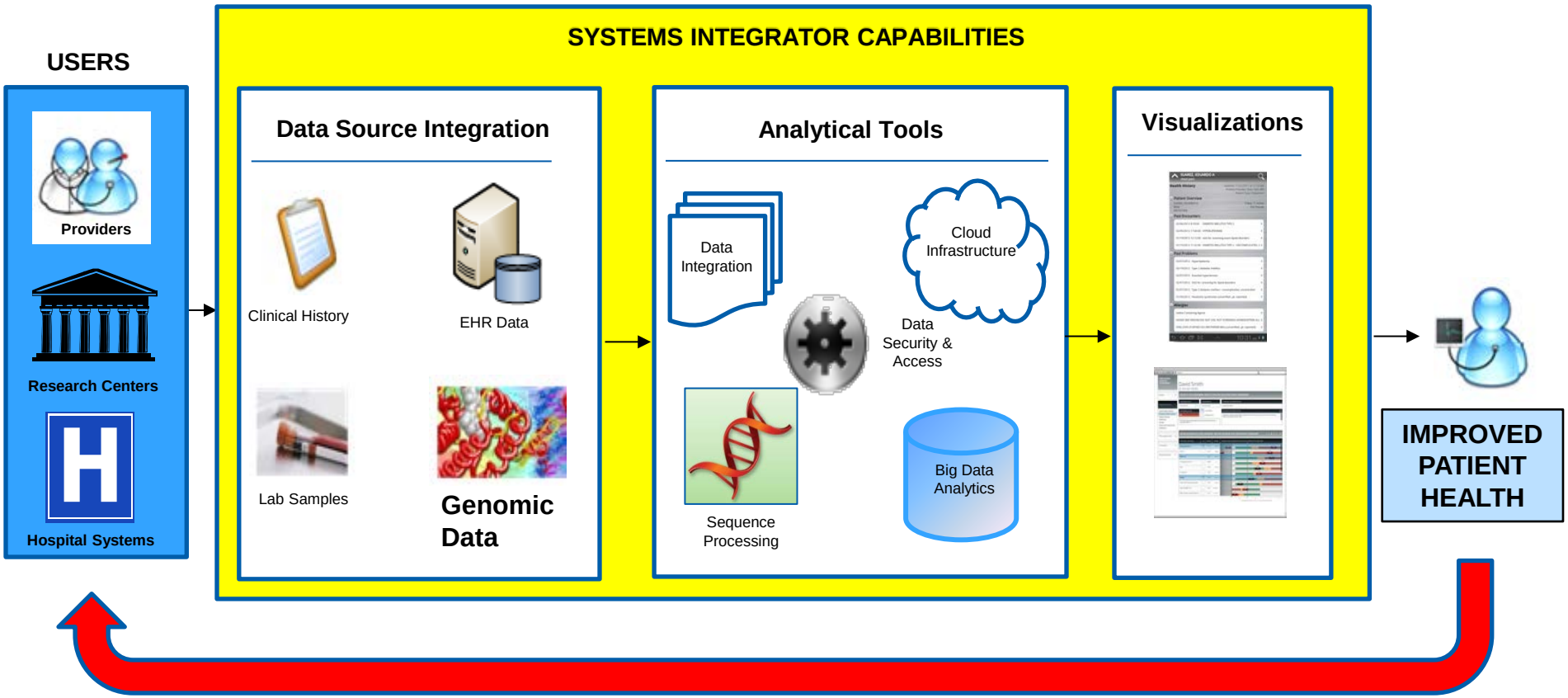
- **Systems Integrators will serve as "genomics enablers"**
  - Leveraging SME and advanced computing expertise to deliver greater value for clinical diagnosis and treatment

Health IT will accelerate Personalized Healthcare as a disruptive force in health and healthcare

Health IT and Knowledgeable Healthcare Systems

Deploying Information Technology within KHCS to facilitate the Genomic Revolution

NORTHROP GRUMMAN



Patient Care Information Feedback Loop

Continuously improving the value and effectiveness of patient care within KHCS

Utilizing Health IT Capabilities to Advance Clinical Research and Care

KHCS(G) – The Clinical Imperative

- How can health systems engage individuals to achieve health using genomic and other technologies?
- How can systems, providers, patients learn from failed efforts to continuously improve health and treatments?
- How can genomic data be used to support patient centered care?
- How can health systems help research and care teams have access to all the data?

KHCS(G) -Issues and Needs

- A data infrastructure that supports both research and clinical care
- Health systems develop a closed loop system that generates *actionable* evidence that genomic tests provide value
- Delivering information at the point of decision to providers
- Genomic and quantitative literacy for patients, providers and researchers
- Clinical decision support and education – engaging the EMR community
- Economic incentives to support the development of such a system
- Not a separate system for genomics

KHCS(G) - Stakeholders

- Providers – learn to use EMR-enabled tools and apply genomic information to clinical decision
- Patients – define preferences about the use of their genomic information
- Researchers – define best practices for research using EMR-linked genomic information
- Policy Makers – address return of results, privacy, confidentiality, and education
- HIT community – design secure genomic enabled/interoperable systems for actionable use in both health care and community settings

Adapted from Ginsburg Nature (2014)

Today's Meeting Objectives

- To explore how key pieces of genetic/genomic information can be effectively and efficiently delivered to patients and clinicians for improving care.
- To discuss how both the health care system and genomic data can be used for evidence generation in research and in patient care.
- To assess current best practices for using knowledge-generating/learning health care systems and which models may provide an opportunity for genomics to be used in the rapid learning process.
- Take-way: The next steps for achieving effective integration of genomic data into the health care systems and the challenges associated with this incorporation