

What is ACCORDS?

Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a 'one-stop shop' for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally



ACCORDS Upcoming Events – mark your calendars!

November 11, 2024 AHSB Room 2007	Emerging Topics in Digital Health & Clinical Informatics Social-Emotional, AI-Powered Avatar Simulations; Improving Communication & Building Empathy for all! <i>Presented by Clint Carlson, MS</i>
December 4, 2024 AHSB Room 2002 3:30-5:00pm MT	Transforming and Advancing a Learning Health System: Multiple Perspectives for Mutual Gain Improving Infectious Diseases Care in Utah: 10 Years in a Learning Health System <i>Presented by Edward Stenehjem, MD</i>
December 9, 2024 AHSB Room 2200/2201	Emerging Topics in Digital Health & Clinical Informatics <i>Presented by Annie Collier, PhD</i>
February 14 & 28, 2025	*New Workshop* ACCORDS/CCTSI Pragmatic Research Planning Workshop Registration coming soon!
Annual Conference June 4-6, 2025 9:00-3:30pm MT	Colorado Pragmatic Research in Health Conference Future of Pragmatic Research: Building Multidisciplinary Teams for Innovation and Impact





Presented by:

Alanna Kulchak Rahm, PhD, MS, CGC

Implementation Science and Precision Health: Maximizing the promise of genomics for health and prevention for all



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Implementation Science and Precision Health

Maximizing the promise of genomics in health and prevention for all

Alanna Kulchak Rahm, PhD, MS, CGC

Program Director, Implementation Science
Division of Genomic Medicine,
National Human Genome Research

November 5, 2024



National Human Genome
Research Institute



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Learning objectives

1. Understand implementation science in the context of genomics and precision health and prevention
2. Identify ongoing research and evidence needs in genomics and precision health
3. Outline ongoing and open funding opportunities

Issues for Precision Health / Genomics

- Evidence is growing rapidly
- Guidelines changing / expanding
- Testing changing / expanding
- Costs decreasing
- Organizations are constantly changing / growing / merging



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How do we evaluate effectiveness and utility and facilitate implementation of programs when evidence and environments are constantly changing?

Implementation Science....

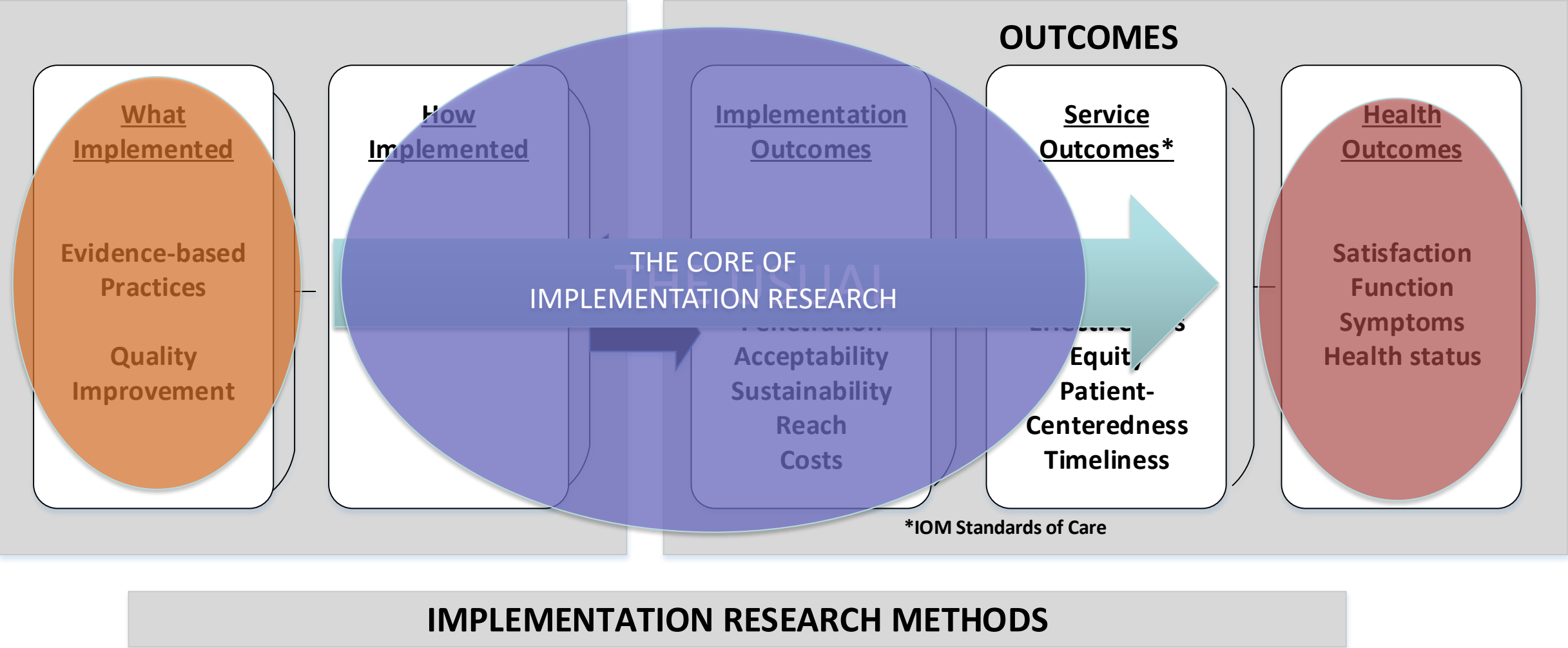
- offers methods and tools to expedite the translation of evidence into routine clinical practice
- can help improve translation of guidelines from development to deployment
- offers designs and evaluation solutions to extract evidence from real world implementations and real-world data
- is integral to operationalization and ongoing functioning of health systems
- integrates tools, designs, and methods for identifying WHAT makes a thing work, WHY does it work, WHEN does it work, and FOR WHOM does it work, and HOW does it work differently in different situations / contexts

What works for who, when, and under what conditions/in what contexts



Studying Implementation

Conceptual Model of Implementation Research



Slide Credit: David Chambers, NCI
Adapted from Proctor (2009) The conceptual model of implementation research

Adapted from Proctor et al (2009)

Implementation Science in a Nutshell

Curran GM. *Implementation Science Communications*. 2020



THE THING

e.g. an intervention, practice change, program, policy



Typical Research

Does THE THING work to improve patient outcomes



Implementation Strategies

What We Do to help people/places do THE THING



Implementation & Service Delivery Outcomes

How Much and How Well people/places Do the THING

“Stages” of Implementation



Where are you and what do you need to do?

Pre-implementation

- Is it feasible? Do costs match available resources?
- Do you stakeholders want it/find it important/does it solve their problem?
- What are the barriers/facilitators? What strategies might address these?

Primary implementation

- How do you make it work?
- What implementation strategies / interventions are you implementing?
- What are your outcomes (effectiveness AND implementation)

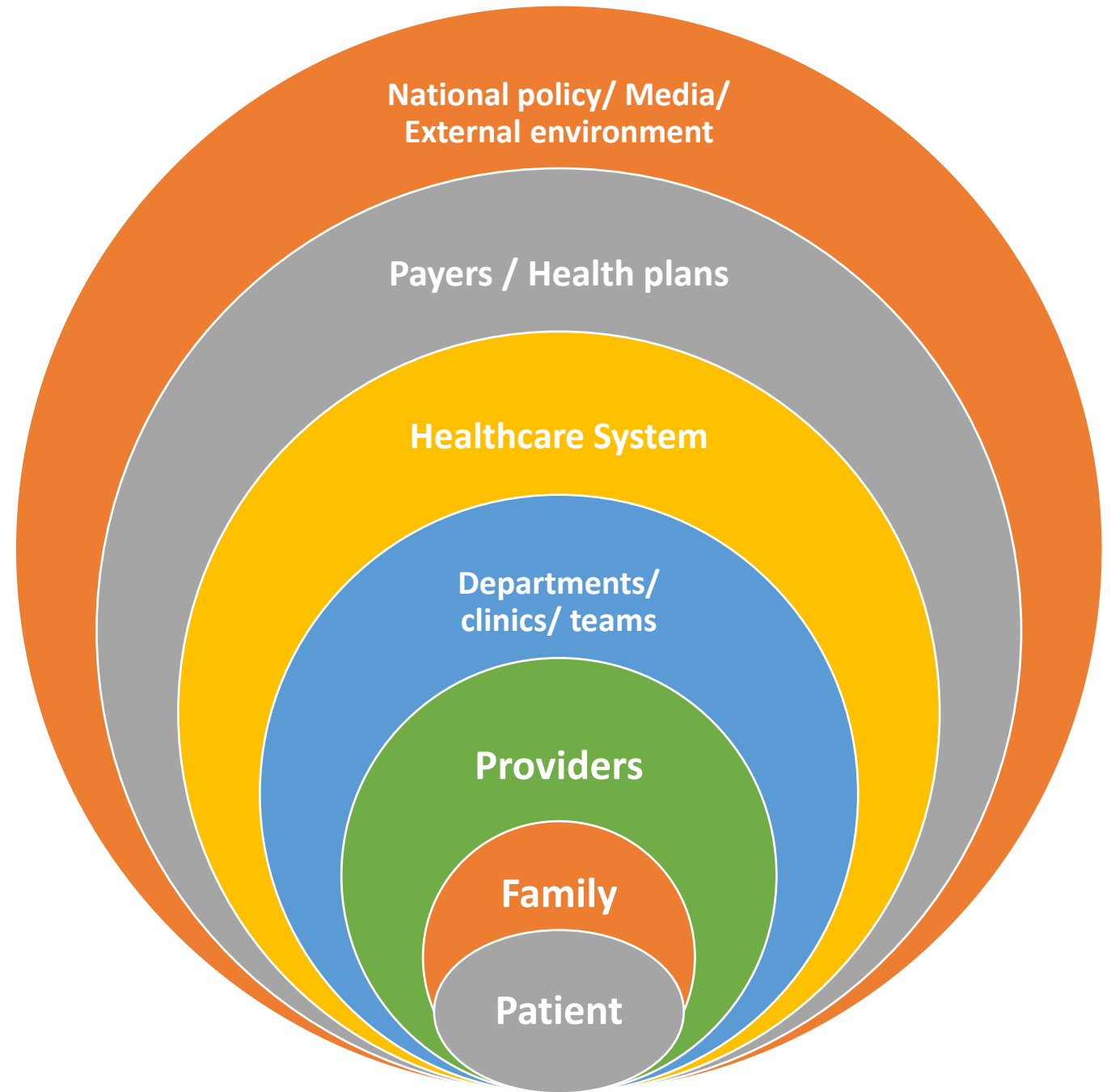
Adaptation & sustainability

- Adaptation vs. voltage drop over time
- Cost/feasibility of sustaining.
- Institutionalization

Evolution / Change

- Ongoing measurement / QA
- Review of new guidelines/tests/options and make decisions to keep as is or evolve/de-implement

Implementing genomic information into care is a multi-level complex issue



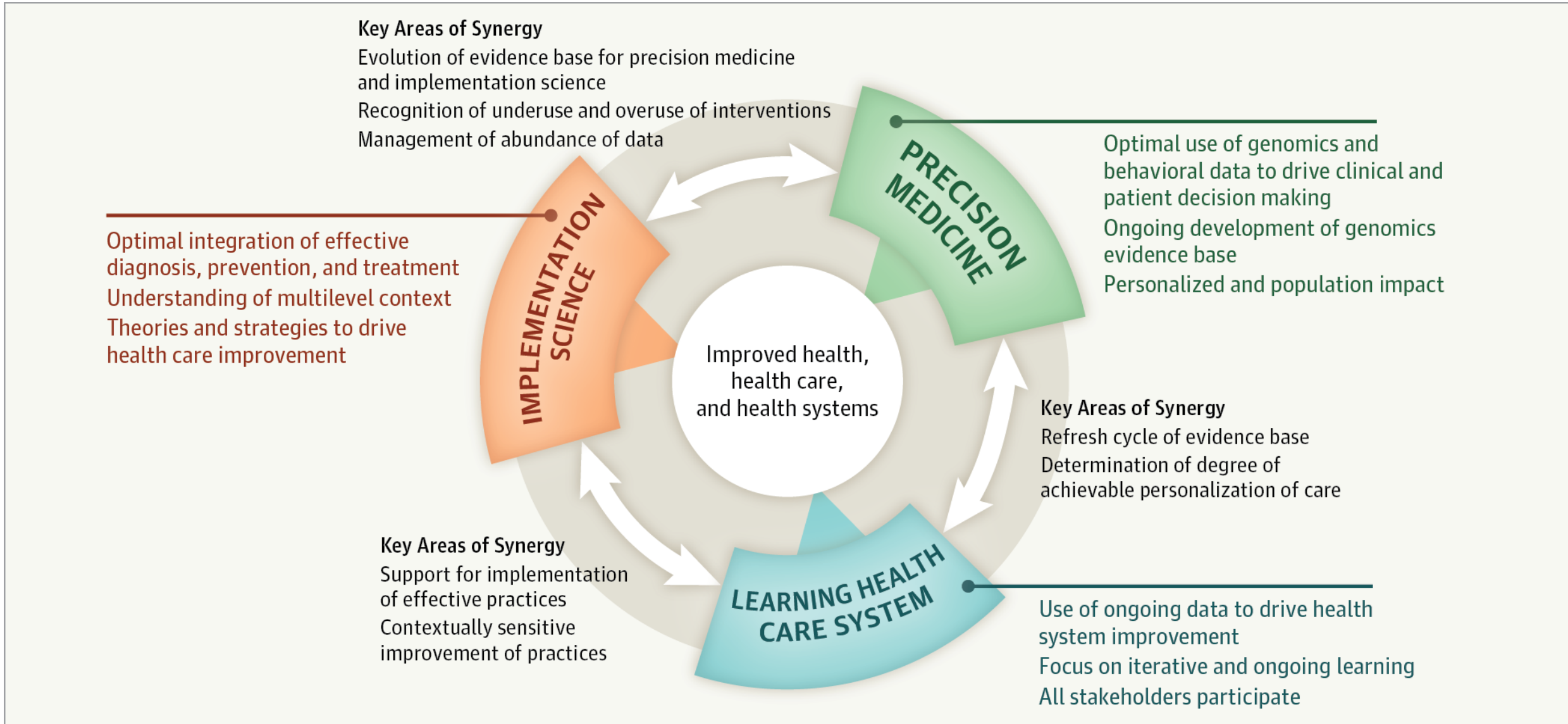
Challenges and Opportunities

“If we want more evidence-based practice, we need more practice-based evidence.”

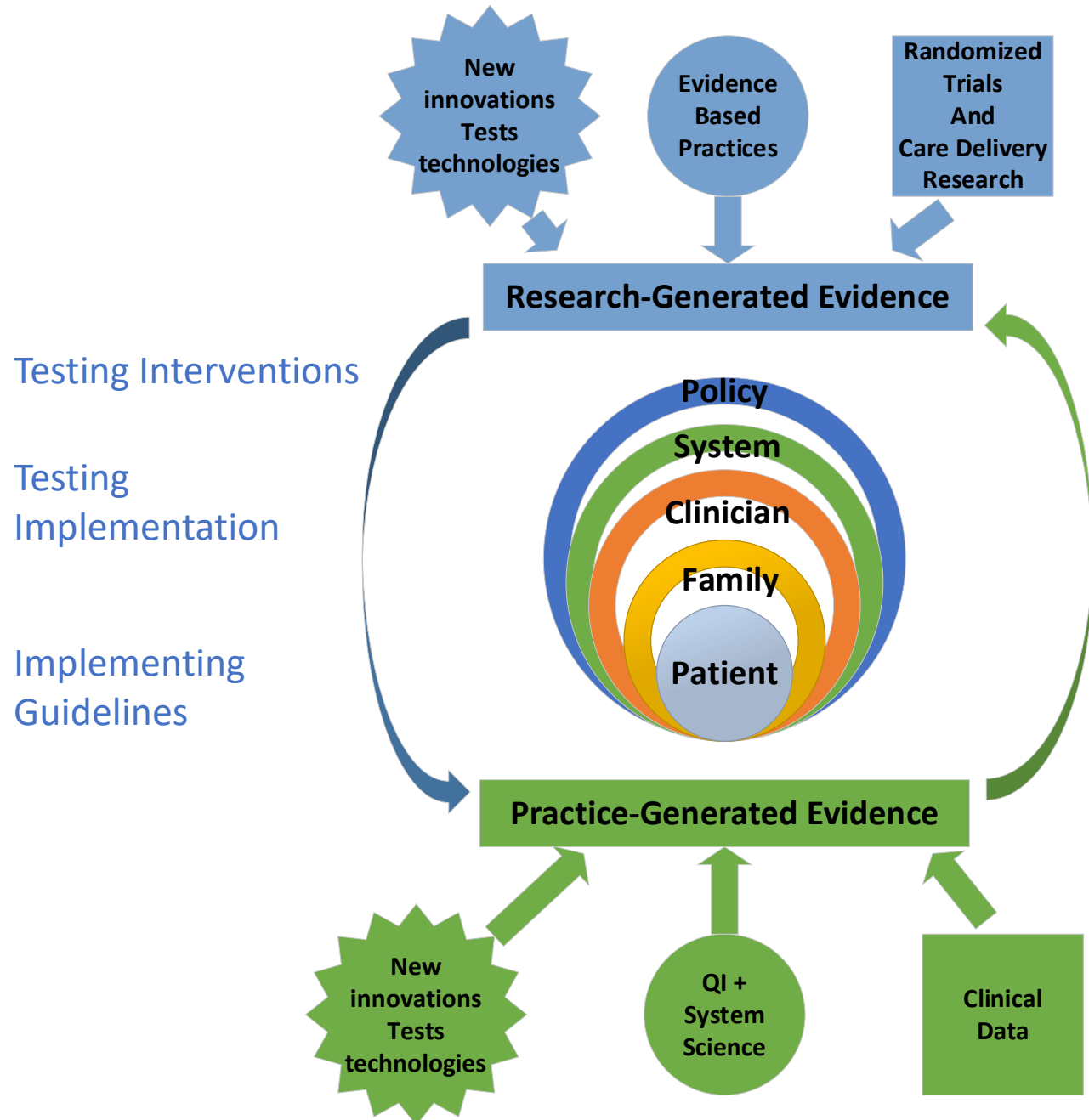
~ LW Green
Am J Pub Health
2006

- Health care and outcomes are inequitable in the “real world”
- Many traditional intervention development trials do not test in clinical settings with staff and processes that are typical to the clinical setting
- Conducting research in the health system can address issues important to clinicians, policy-makers, and patients
- Conducting research in the health system (in context) can identify process issues, patient-level issues, and clinic/clinician level issues, and system level issues and how they interconnect to impact whether, how (or not), and for whom innovations/interventions work to improve health
- Ongoing evaluation in a learning health system environment can identify need for change, adaptation, evolution, or even de-implementation of programs

Contributions of Implementation Science, Learning Health Care System, and Precision Medicine



A Learning Health System Operationalized to Generate Evidence from Practice and Implement Evidence into Practice Through Continuous Learning and Research



Trialing feasibility and generating data for externally funded Research

Optimizing Real world use/outcomes

Hypothesis/program generating



Policy Implementation in Genomics

- Think of policy as THE THING
- Shifts the policy/guideline from the outer setting
- How much and how well people and places implement the policy/guideline
- What they do to implement the policy/guideline



Implementation Science is a Toolbox

- Theories, models, frameworks
- Study designs
- Multiple methods
- Intervention / implementation mapping
- Adaptation tracking / reporting
- Engagement methods



Engagement – a core component



Co-creation with those who
will benefit most



Engagement across spectrum
of Implementation



Mitigate biases from big data

Recommended IS Components to Incorporate Equity into Precision Medicine and Public Health



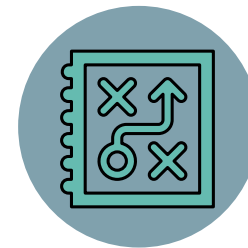
Stakeholder
Engagement



Evaluation Approaches



Models &
Frameworks



Implementation
strategies



Develop, Select, Adapt EBPs

Hint: it's not always about a primary implementation design

Select the Theory, Design, and Methods that “Fit”



“All models are wrong...
some are useful”

❖ George E P Box



What is going on?



What is important to the
stakeholders?



How much control do you
have? And what's the
important question?

Genomic Medicine and Precision Health Implementation Paradigm Shift



Beyond building it:

- Knowing is not enough, understanding is not enough, access (making it available) to testing is not enough
- Increasing diversity in those tested / with genomic information
- Must facilitate USE of the information within existing care processes and address any disparity created



There is no ONE best practice:

- Implementation is local, but core “function” can be consistent across systems
- Strategies exist that facilitate the desired function in different situations and contexts



“NEXT mile” not “last mile” thinking

- Sustaining, improving, optimizing, de-implementing, adapting, incorporating new information to improve health is an ongoing cycle
- The LHS/gLHS is the environment for ongoing implementation outcome and effectiveness outcome measurement

Implementation Outcomes measured throughout learning cycles regardless of where in the translational or implementation spectrum the genomic innovation is entering the cycle



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ABOUT
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RESEARCH
FUNDING



RESEARCH
AT NHGRI



ABOUT
HEALTH



CAREERS &
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NEWS &
EVENTS



ABOUT
NHGRI

...Begin your search here



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Division of Genomic Medicine

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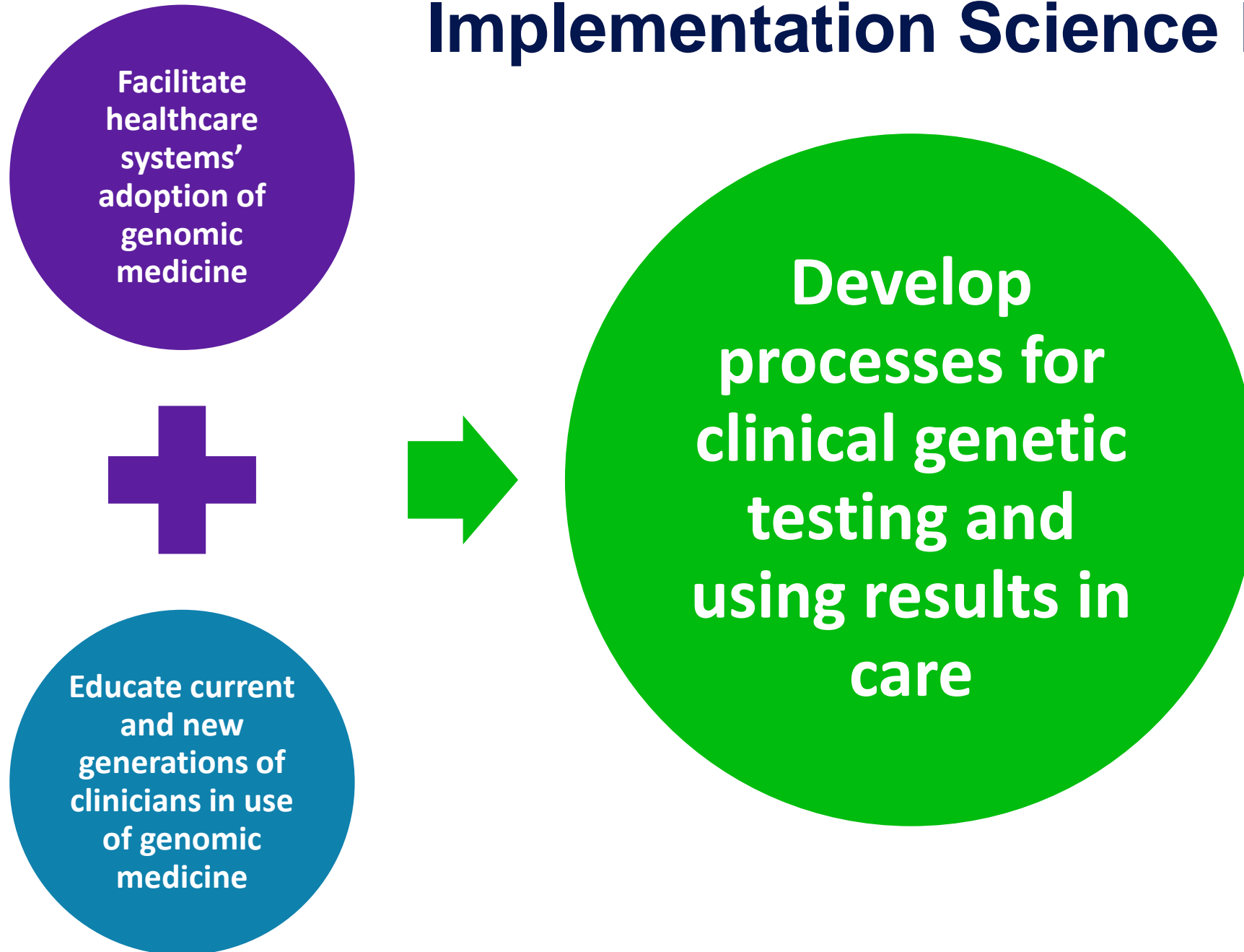


promotes the institute's efforts to advance the application of genomics to medical science and clinical care



plans, directs and facilitates multi-disciplinary research to identify genetic contributions to human health and to advance approaches for the use of genomic data to improve diagnosis, treatment and prevention of disease

Implementation Science Funding



Monday, September 23, 2024

NIH awards \$27M to establish new network of genomics-enabled learning health systems

Network will analyze and improve how genomic information is integrated into patient care.

The National Institutes of Health (NIH) is awarding \$5.4 million in first-year funding to establish a new program that supports the integration of genomics into learning health systems.

Present in many hospitals across the United States, learning health systems are a type of clinical practice that bridges research and patient care. These systems use a variety of methods to continually analyze patient data. Clinicians then use the results of those analyses to refine practices and improve future care.



Genomics + Learning Healthcare System + Implementation Science = **Genomics-enabled LHS**

Genomics:



- Evidence, technology, and genomic knowledge continue to grow rapidly
- This requires ongoing learning and evidence development coexisting with implementation of genomics

Learning Healthcare system:

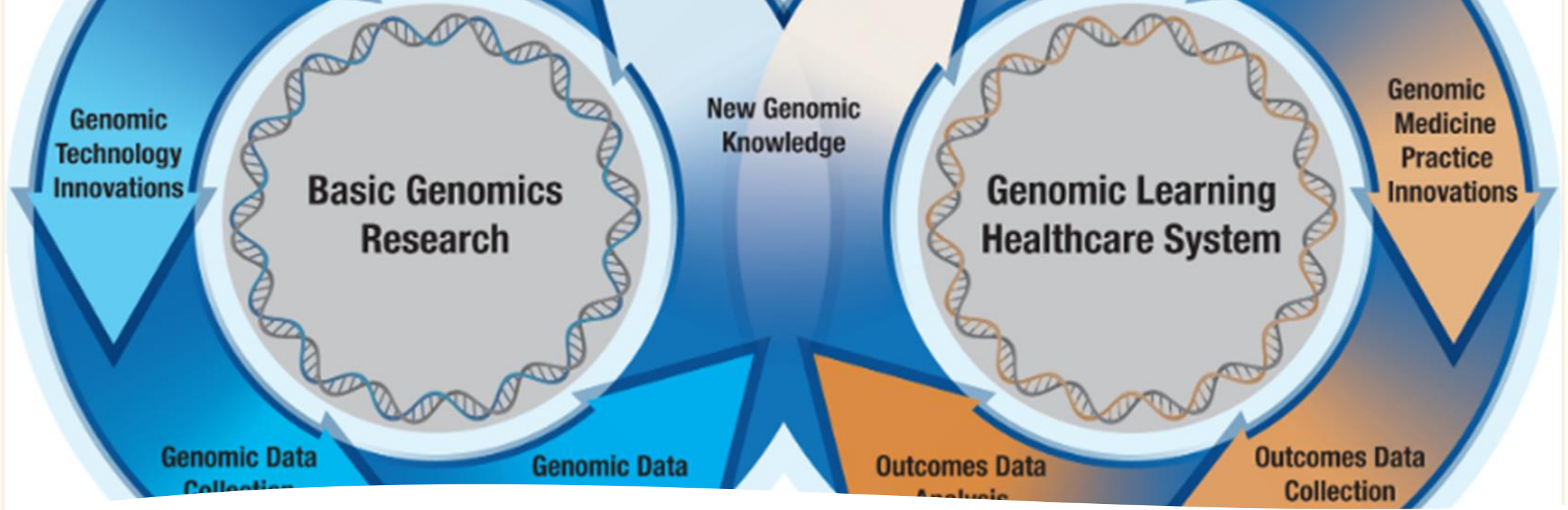


- Research and practice can co-exist
- Each can inform the other, each can generate questions and evidence
- Culture and informatics to measure, analyze, report, adapt, evolve

Implementation Science



- Provides framework and strategies for implementing genomics
- Focus on context, multilevel factors, real-world sustainability, collaboration of stakeholders (including patients and families)



Network Objective

- Refine and develop existing LHS and genomics practices into implementation resources
- Identify and implement 2-4 Network-wide genomic medicine intervention projects
- Use these projects to increase system-wide and across health systems interoperability and refine resources for broader sharing of genomic medicine implementation practices
- Establish tools and resources for sites implementing a gLHS

Open Funding Opportunities

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Population Genomic Screening in Primary Care

[RFA-HG-24-021](#): Clinical sites

[RFA-HG-24-022](#): Coordinating center

[RFA-HG-24-023](#): Sequencing Center

[Webinar](#) – recorded 10/10/2024

App. Due Date - December 02, 2024



*Advancing Genomic Medicine Research (AGMR)

R01: [RFA-HG-23-032](#), R21: [RFA-HG-23-033](#), R03: [RFA-HG-23-048](#)

*Dissemination and Implementation Research in Health

R01: [PAR-22-105](#) , R21: [PAR-22-109](#) , R03: [PAR-22-106](#)

Funding Opportunity - Small Business Program



National Human Genome
Research Institute

Small Business Program



Specific NOSI / PAR:

Solutions to Enable Population Genomic Screening

[PAR-24-262](#): STTR

[PAR-24-263](#): SBIR

Notice of Special Interest:

[NOT-HG-24-040](#): Small Business Solutions to Assist
Genomics-Enabled Learning Health Systems (gLHS)

[NOT-HG-24-002](#): Advancing Genomic Medicine
Research through Small Businesses



NIH-ACMG Fellowship in Genomic Medicine Program Management



- Full-time, two-year, and paid experience
- Acquire credentials and experience to lead genomic medicine research and implementation programs
- Open to qualified physicians, physician assistants/associates, advanced practice nurses, and genetic counselors
- Post-fellowship positions include the NIH, WHO, and major medical institutions

Applications Due Date: December 6, 2024

nihacmgfellowship@nih.gov



ASHG-NHGRI Post-Baccalaureate Genomics Analyst Fellowship



- Full-time, two-year, and paid experience
- Starts July 1, 2025
- Earned BA/S within 3 years
- Eligible to work in the US

Applications Due Date: January 5, 2025

fellowships@ashg.org

Individual Awards: Training and Career Development

Who to contact: Heather Colley, heather.colley@nih.gov

Graduate / predoctoral

- Fellowships (F30, F31)
 - Fellowships, diverse backgrounds (F31-D)
- Predoc to postdoc transition, diverse backgrounds (F99/K00)

Postdoctoral

- Fellowships (F32)
- Postdoc to faculty (K99/R00)
- Postdoc to faculty, diverse backgrounds (MOSAIC K99/F00)

Early and mid-stage investigator

- Workforce diversity (R01)
- Mentored research scientist (K01)
- Loan repayment program (LRP)

Specific professional focus

- Mentored clinical scientist (K08)
 - Quantitative Scientist (K25)

← Diversity, re-entry, and re-integration administrative supplements →



NIH Loan Repayment Program

- **NOFO:** <https://www.lrp.nih.gov/>
- Recruit and retain qualified health into biomedical or behavioral research careers relevant to NHGRI's research mission.
 - **Clinical research (L30, L32):** patient-oriented clinical research with human subjects or research on disease in human populations involving material of human origin.
 - **Pediatric Research (L40):** research directly related to diseases, disorders and other conditions in children, including pediatric pharmacological research.
 - **Health Disparities Research (L60):** research that focuses on one or more of the minority health disparity populations defined by NIMHD and the Agency for Healthcare Research and Quality
 - **REACH (L70): genetic counselors at master's and doctoral level involved in genomics research *only at NHGRI***
- Open to U.S. citizens, nationals or permanent residents. **Do not have to be supported on an NIH grant.**
- **Budget:** Up to \$50K annually

Due Date – November 21, 2024

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NHGRI Funding Opportunities

<https://www.genome.gov/research-funding/Funding-Opportunities>

NIH Central Resource for grants and funding information

<https://grants.nih.gov/funding/searchguide/index.html#/>



Genomics and Precision Public Health Training Courses



Training Institute for Dissemination and Implementation Research in Genomics and Precision Public Health (TIDIR-GPPH) Facilitated Course

The goal of the TIDIR-GPPH training institute is to provide participants with a thorough grounding in conducting Dissemination and Implementation Research in the specific focus areas of genomics, genomic medicine, and precision public health.

Division of Genomic Medicine

Marcus Brown
 Christine Chang
 Jessica Chong
 Heather Colley
 Priscilla Crockett
 Jyoti Dayal
 Carmen Demetriou
 Adrienne Green
 Eric Green
 Peggy Hall
 Deanna Ingersoll
 Rongling Li
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 Geoff Ginsburg, Gillian
 Hooker, Gail Jarvik,
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Genomic Medicine Program Investigators and Participants



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Thank You



The **Forefront**
of **Genomics**[®]