

MITIGATING INEQUITIES IN
SCREENING FOR
HEREDITARY CANCER
SYNDROMES

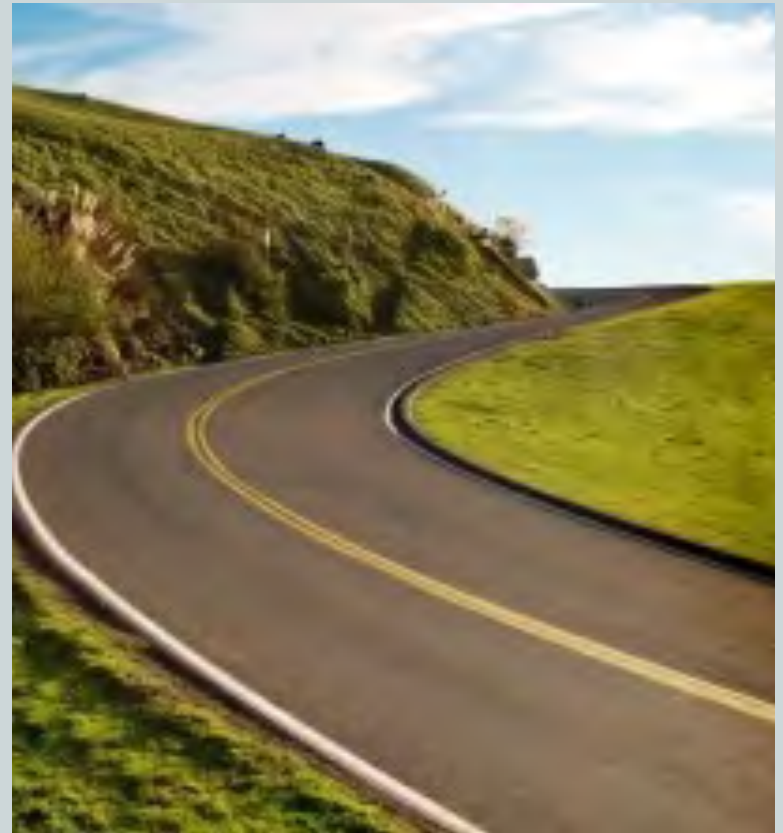
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SCREENING FOR HEREDITARY CANCER SYNDROMES

- A growing body of evidence has shown that screening for hereditary cancer syndromes can improve clinical care and enhance overall population health.
- Routinizing appropriate screening remains difficult.



DISPARITIES IN *UTILIZATION* OF HBOC SCREENING

- Advent of genomic technologies may exacerbate health disparities, if those technologies are not available to everyone.
- The American BRCA Outcomes and Utilization of Testing (ABOUT) study showed that among women whose clinicians ordered comprehensive BRCA testing, most were white, college educated, married, and wealthier (Armstrong et al. 2015).
- White women are far more likely to receive screening than racial/ethnic minorities.
- Concerns that low-income and uninsured patients also face barriers accessing services.



CONFLICTING TERMINOLOGY

Opinion

VIEWPOINT

Genomics, Health Disparities, and Missed Opportunities for the Nation's Research Agenda

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The completion of the Human Genome Project occurred at a time of increasing public attention to health disparities. In 2004, Sankar and colleagues¹ suggested that this coincidental timing resulted in an inappropriate emphasis on the contribution of genomics to health disparities, conflating racial patterns of disease with genetic ancestry, and distracting attention from the large and compelling body of scientific evidence pointing to social determinants of health disparities.² For example, genomic research has emphasized discovery of genetic contributors to diabetes risk, but the recent increase in the prevalence of obesity and type 2 diabetes, which disproportionately affects minority populations, cannot be attributed to genetic changes and rather reflects social forces affecting diet, food access, and patterns in physical activity. The introduction of new genomic health technologies could also exacerbate disparities in access to

considerable attention among policy makers and the general public. Yet this large body of knowledge is absent from genomics discourse, which remains largely focused on biological causes and biomedical interventions.⁴

Health care plays a crucial role in decreasing morbidity and mortality once disease processes are under way, but accounts for only a minor portion of population health status. A study comparing the major determinants of health estimated that only 10% to 15% of premature mortality could be prevented by improved or more medical care.⁶ The limits of health care were demonstrated in a statistical experiment, comparing deaths potentially averted if people were to have a college education vs those potentially averted by advances in health care technology and an 8-fold difference was found favoring education.⁷ Moreover, the kind of health care that makes the largest difference to population health

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Health disparities are generally understood to refer to systematic differences in health effects resulting from social disadvantage, but the term is often used in genomics to refer to differing health outcomes associated with population genetic variation. This usage argu-

contributors to diabetes risk, but the recent increase in the prevalence of obesity and type 2 diabetes, which disproportionately affects minority populations, cannot be attributed to genetic changes and rather reflects social forces affecting diet, food access, and patterns in physical activity. The introduction of new genomic health technologies could also exacerbate disparities in access to

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DEFINING HEALTH *INEQUITIES*

- ▶ Health inequities are a subset of health disparities that are modifiable, **associated with social disadvantage**, and considered ethically **unfair**.

- ▶ *Arcaya, Arcaya, and Subramanian, 2015*

- Health inequities should be viewed as the **end result of a chain of events** signified by difference in:
 - Environment
 - Access to, utilization, and quality of care
 - Health status
- Involves assessing:
 - Avoidability
 - Ethical judgments

INTEGRATED FRAMEWORK

- We propose an integrated framework for future research, intervention, and policy work that will mitigate inequities in genomic medicine, including for cascade screening.
 - Hereditary Breast & Ovarian Cancers (HBOC) as a case example.



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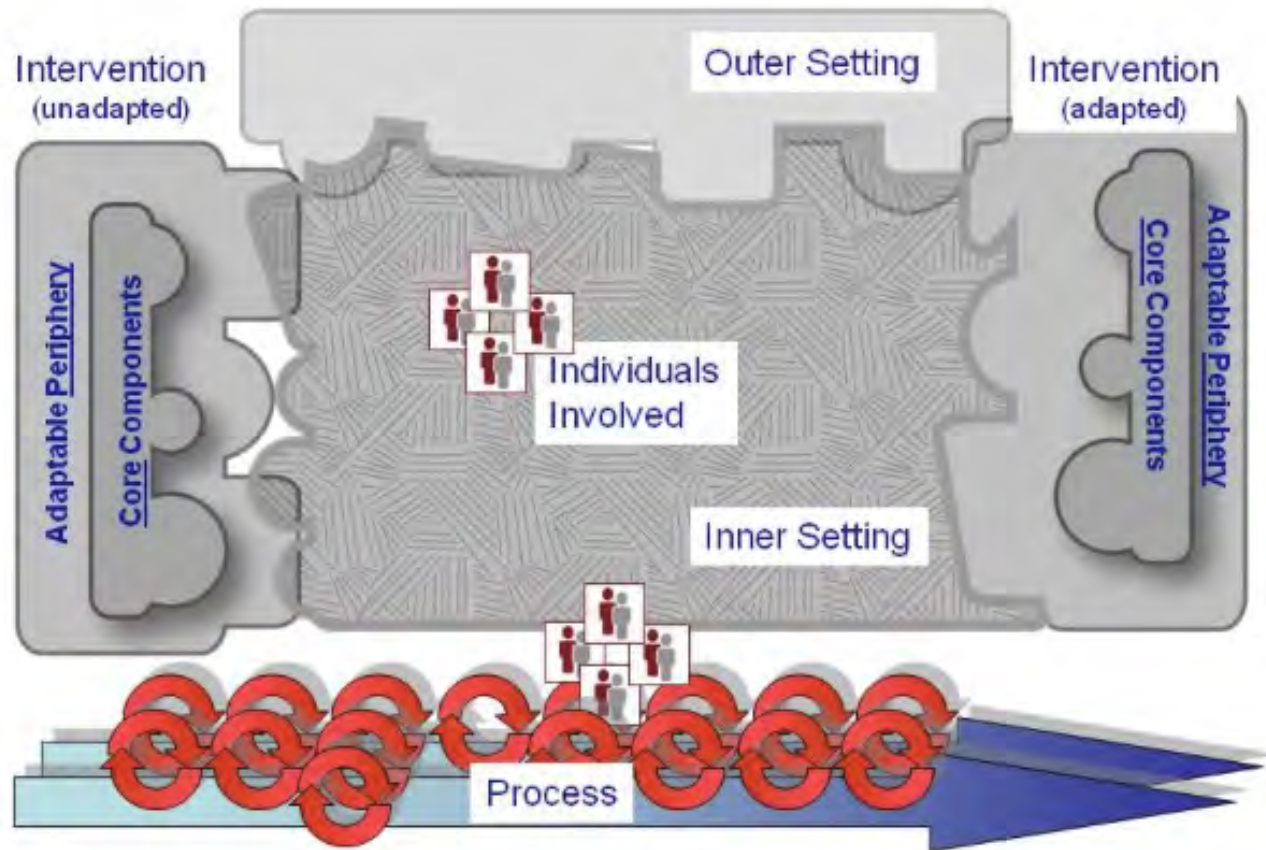


Article

Blending Insights from Implementation Science and the Social Sciences to Mitigate Inequities in Screening for Hereditary Cancer Syndromes

Laura Senier ^{1,2,*}, Colleen M. McBride ³, Alex T. Ramsey ⁴, Vence L. Bonham ⁵ and David A. Chambers ⁶

THE CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH



GENOMICS, POPULATION
HEALTH, AND HEALTH
INEQUITIES

*When is
public
health
action
warranted?*

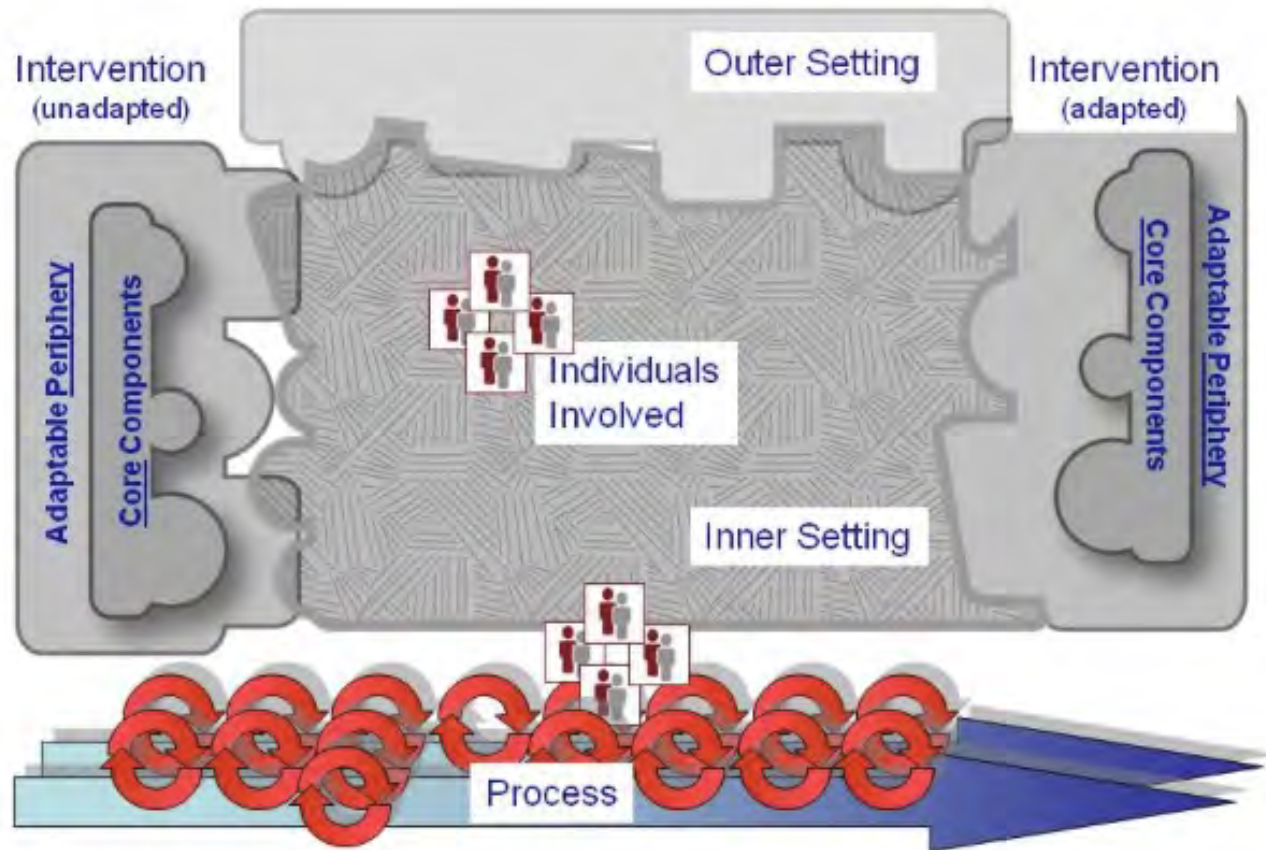
CDC'S FRAMEWORK FOR ACTION IN PUBLIC HEALTH GENOMICS

Genomic Application	Tier 1: Clinical Practice Guidelines/ Systematic Review	Tier 2: Clinical Practice Guidelines / Insufficient Evidence	Tier 3: Clinical Practice Guidelines Recommends Against
Example	Hereditary breast & ovarian cancers	FHH in primary care	Genetic tests marketed DTC
Public health burden	5-10% of all cases annually; early age @ onset	FHH common risk factor for many chronic diseases	Numerous companies selling such tests
Expert panel recommendation	Offer genetic counseling to women with a strong family history of the disease (USPSTF 2005)	FHH can prompt behavior change; unclear impact on outcomes (NIH 2009)	Insufficient evidence on clinical validity/utility (CDC-NIH conf 2009)
Public health action	Promote implementation; Develop clinical decision support tools	Provide info; educate patients and providers	Measure use of DTCA tests; discourage use by patients and providers

IMPLEMENTATION SCIENCE

- Methods to implement evidence-based interventions, policies, and practices into routine clinical care public health programming.
 - Subject those interventions to rigorous evaluation
- Identify things that promote or hinder the adoption of evidence-based practices and policies.
- Leverage this knowledge to improve healthcare delivery and healthcare quality.

THE CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH

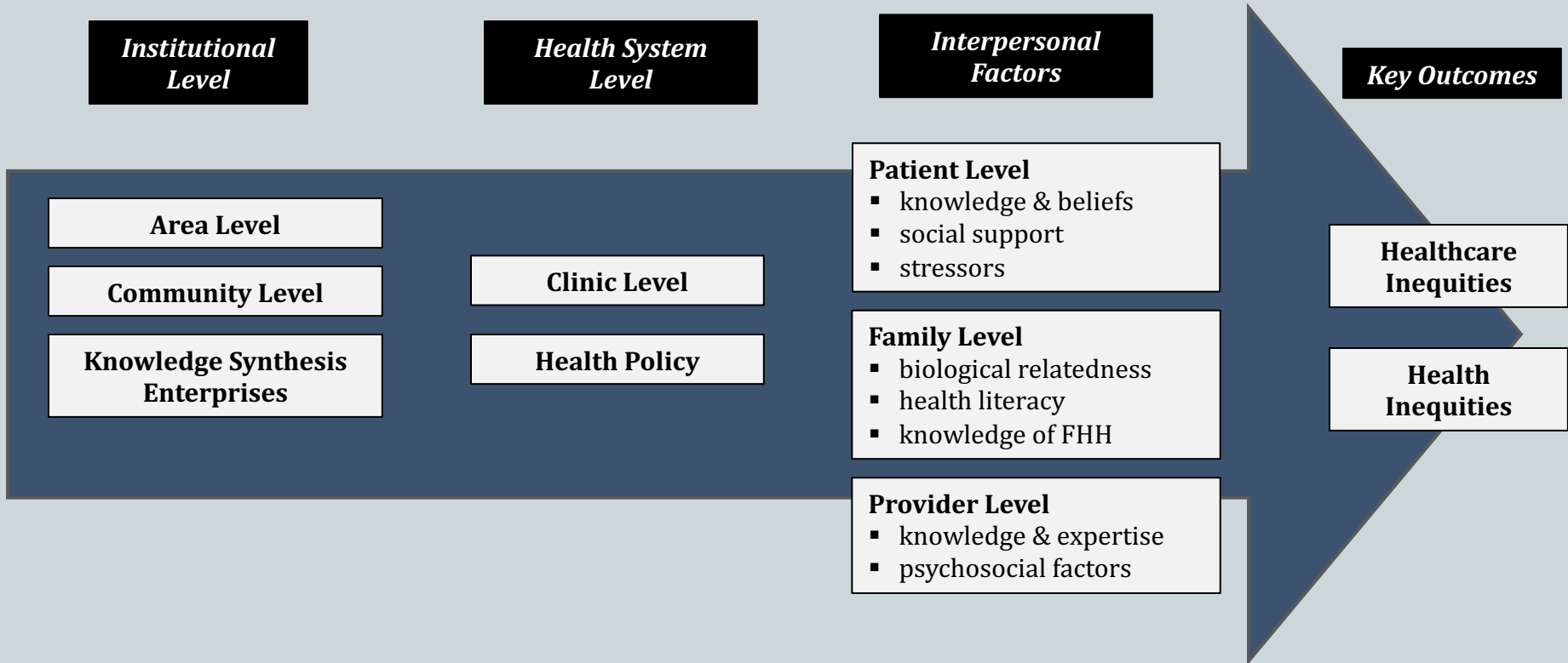


SIX CATEGORIES OF IMPLEMENTATION STRATEGIES

Category	Examples
Planning	<ul style="list-style-type: none">• Build buy-in (involve patients/family; conduct local consensus meetings)• Develop relationships (coalition building; develop resource-sharing agreements)
Educating	<ul style="list-style-type: none">• Develop/distribute materials; Inform local opinion leaders
Financing	<ul style="list-style-type: none">• Reduce/increase patient fees; penalize providers for failure to follow best practices
Restructuring	<ul style="list-style-type: none">• Create new clinical teams; change service sites
Managing Quality	<ul style="list-style-type: none">• Audit/provide feedback; remind clinicians; use data warehousing techniques
Attending to the Policy Context	<ul style="list-style-type: none">• Change accreditation/membership requirements; create/change credentialing standards or licensure requirements

FUNDAMENTAL CAUSE THEORY

- Social conditions should be viewed not as nuisance variables to be controlled for, but as conditions that are fundamentally related to disease causation.
 1. Related to multiple disease outcomes
 2. Operate through multiple risk-factor mechanisms
 3. Involve access to resources that can be used to avoid risks
 - “people with superior resources can use those resources to garner health advantages.”
 4. New intervening mechanisms reproduce the association between causes and outcomes over time
 - “the specific mechanisms that allow advantage to accrue change from place to place and from time to time.”



Fundamental Causes

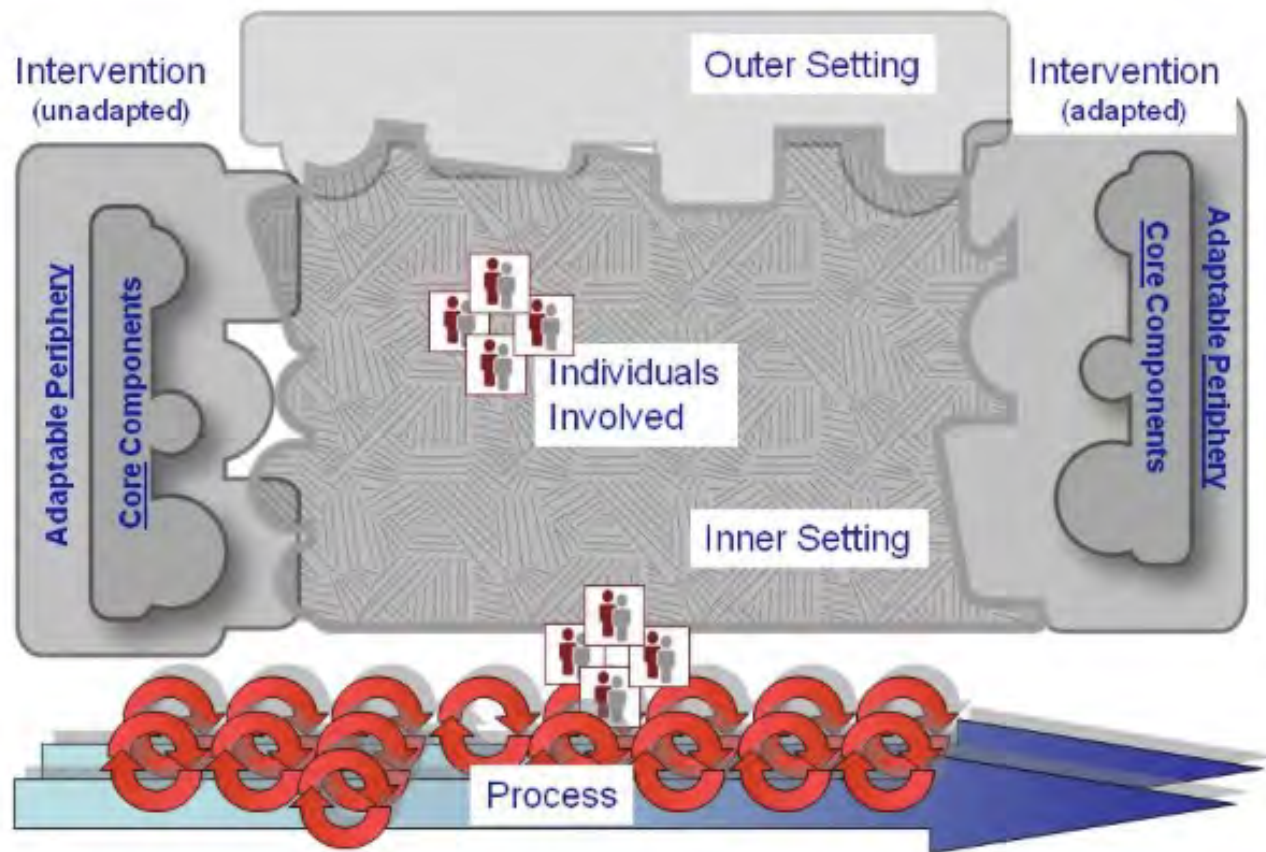
Geographic maldistribution of primary and specialty healthcare services

Inequities in power and ability to influence healthcare policy

Inequitable distribution of wealth, educational opportunities, employment opportunities

ADAPTING
IMPLEMENTATION
SCIENCE FRAMEWORKS
TO ADDRESS HEALTH
INEQUITIES

THE CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH



Outer Setting

Area Level
Community Level
Health Policy
Knowledge Synthesis

Inner Setting
Clinic Level
Individuals



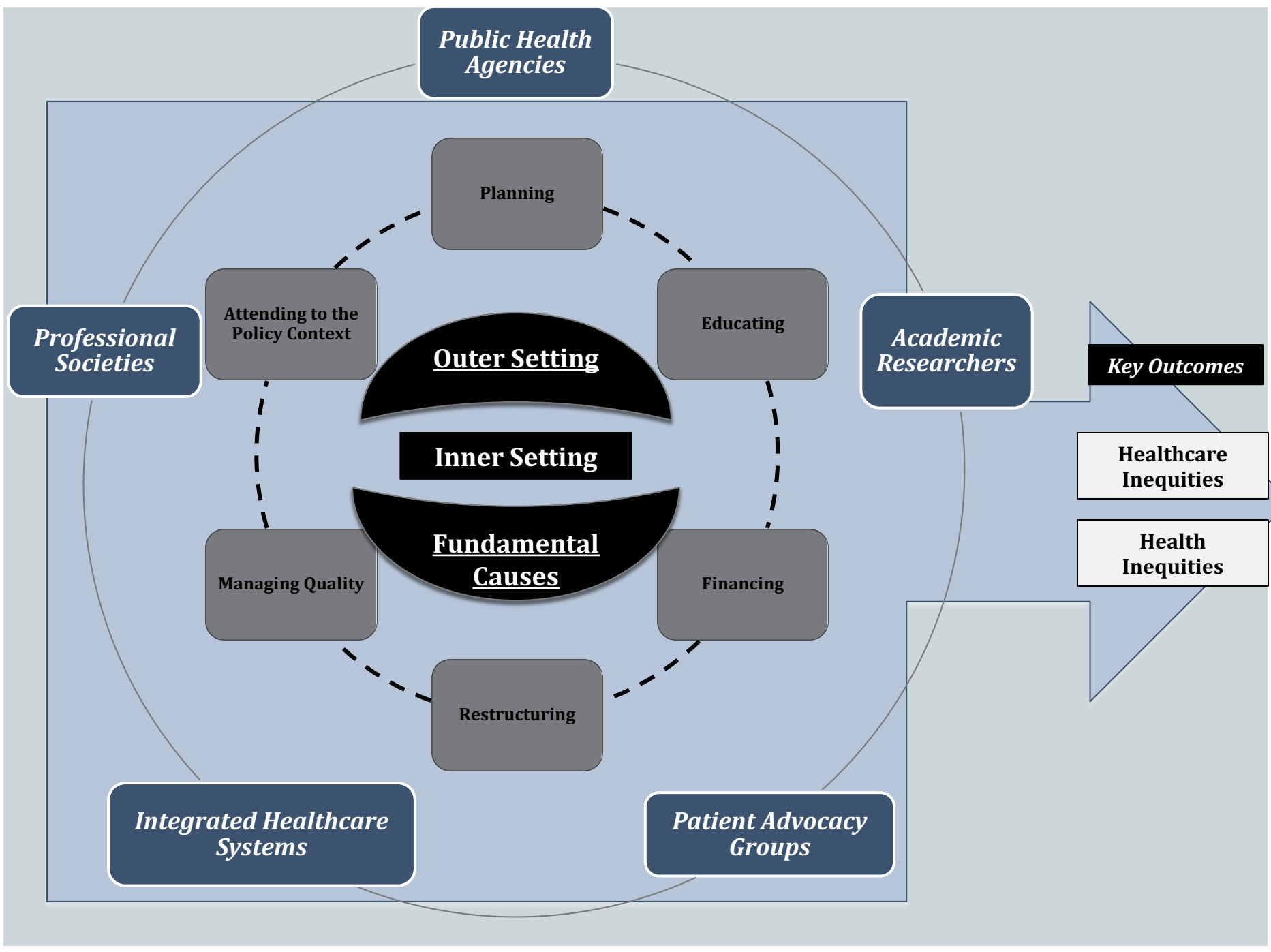
Fundamental Causes

Maldistribution of services
Inequities in resources
Power differentials

Key Outcomes

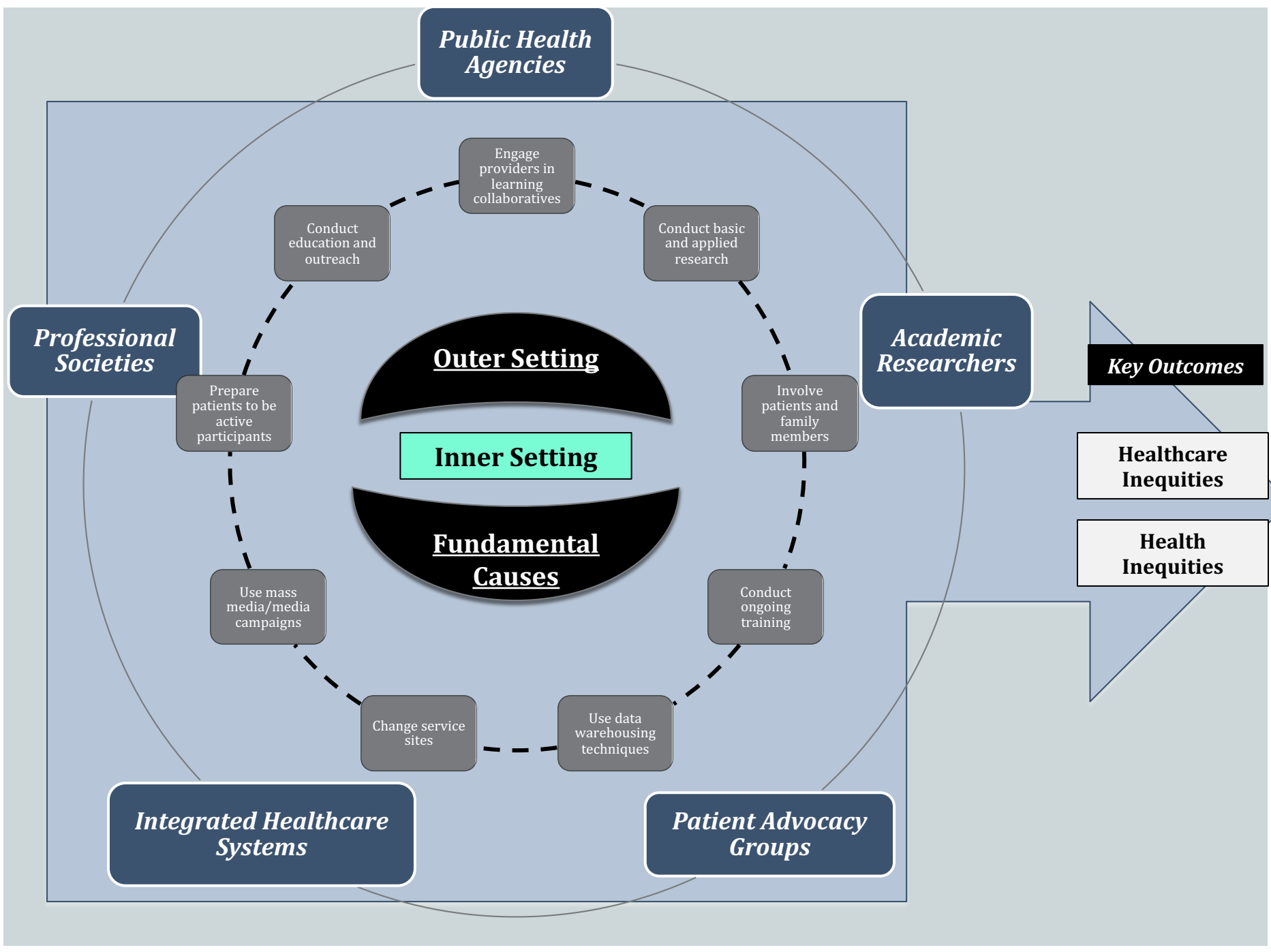
**Healthcare
Inequities**

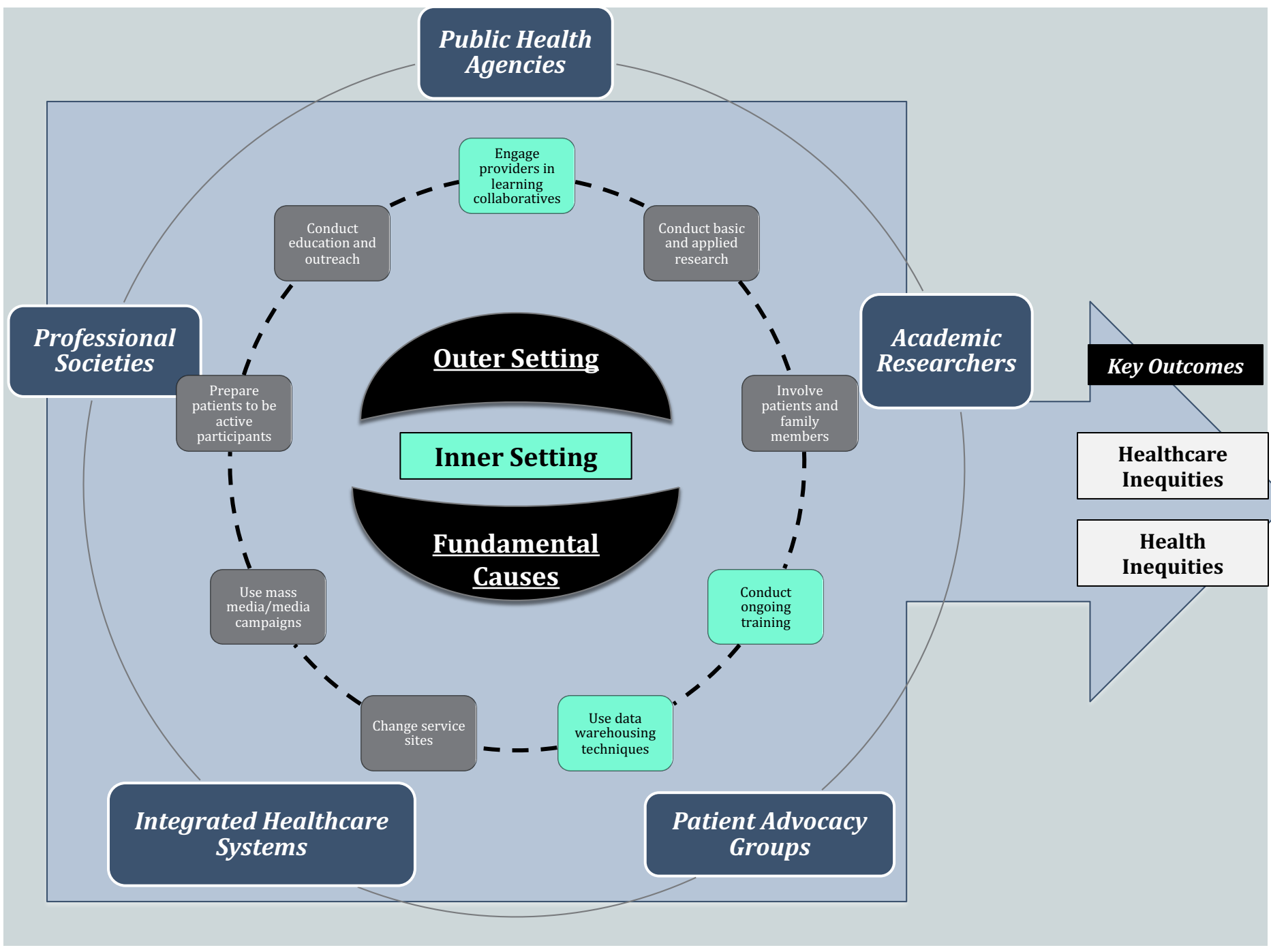
**Health
Inequities**

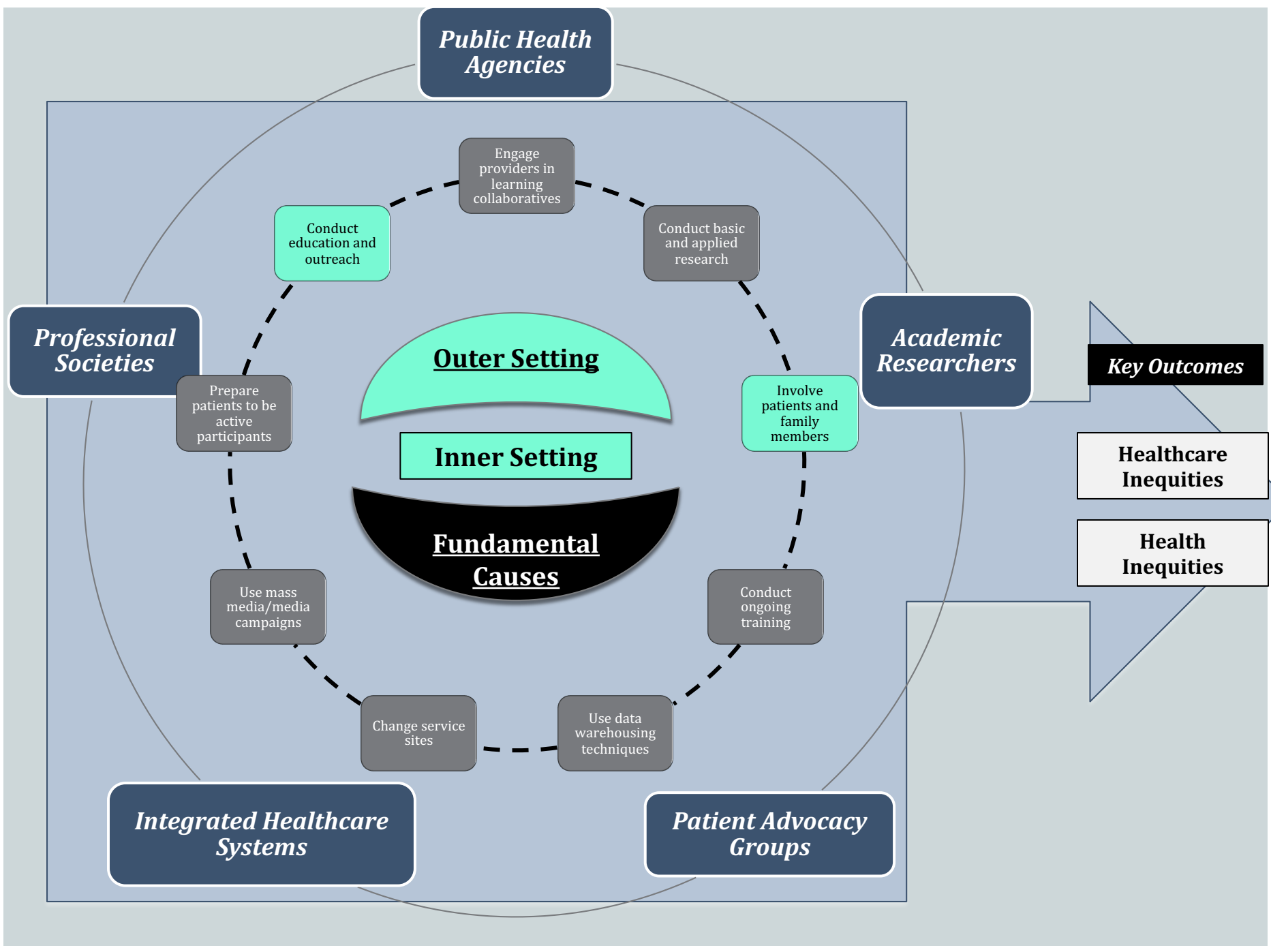


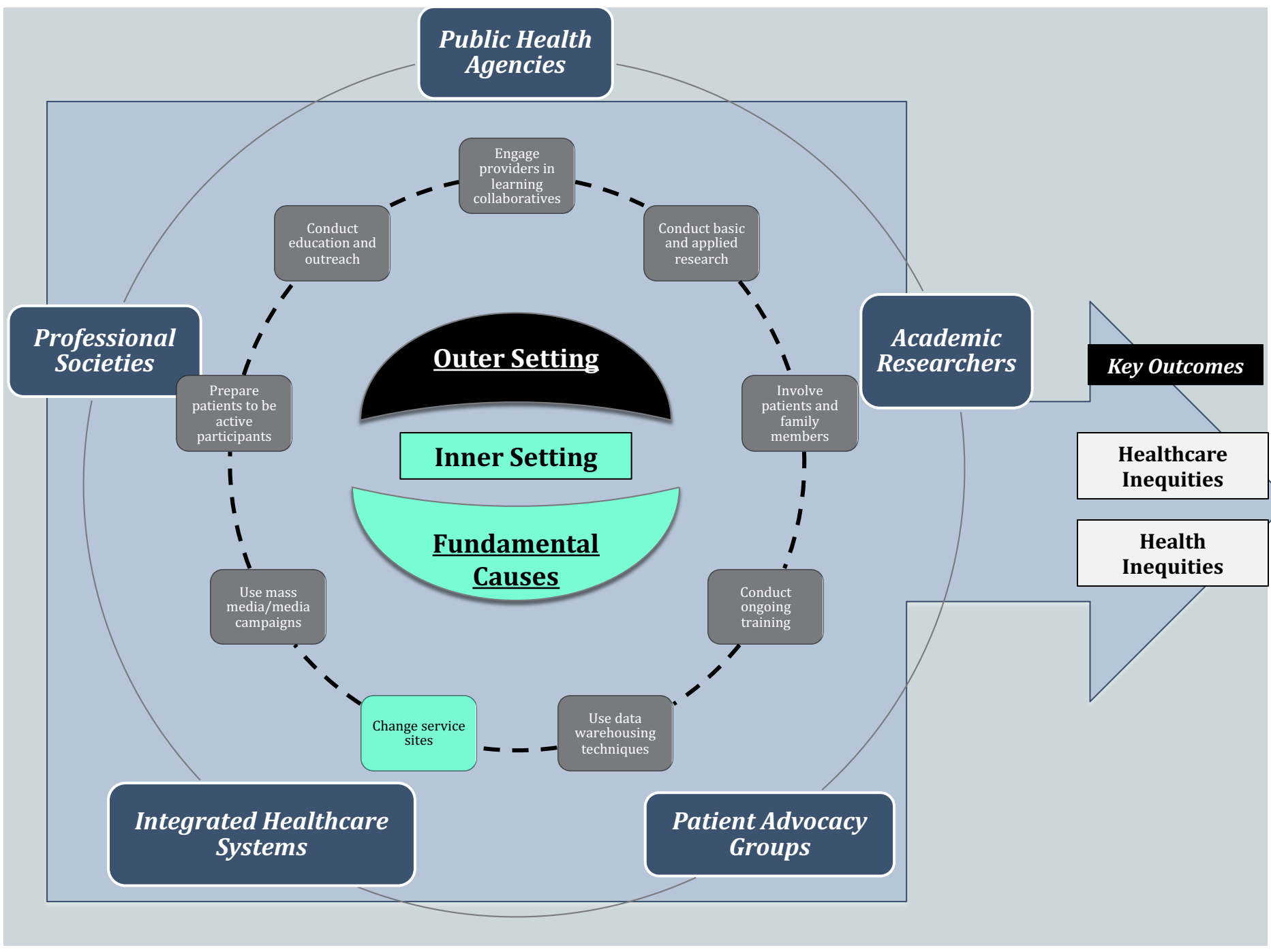
APPLYING THE
INTEGRATED
FRAMEWORK TO
IDENTIFY BARRIERS IN
HBOC SCREENING

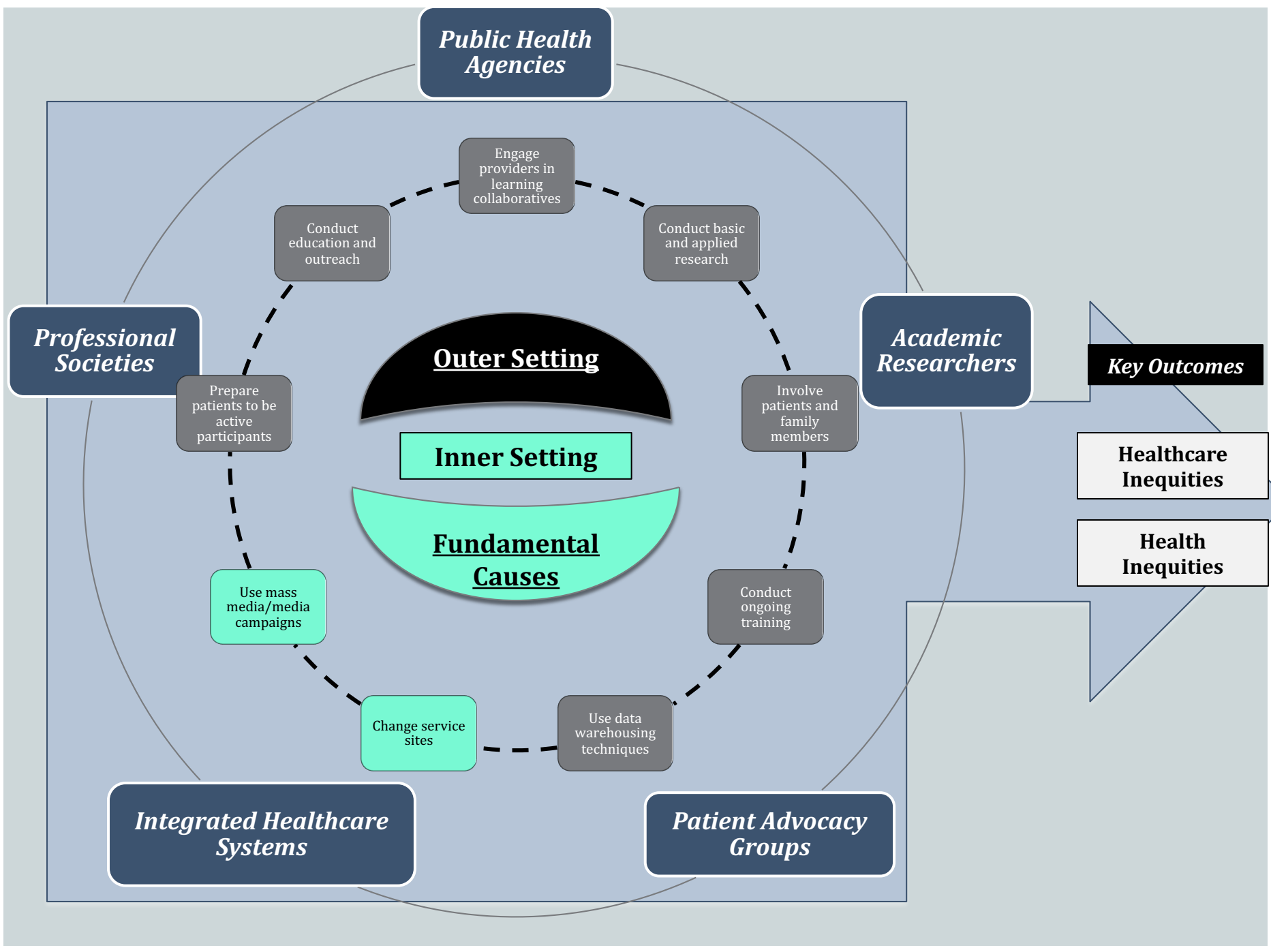
Examples











CONCLUSIONS

- We argue that mitigating health inequities will require addressing not only individual-level influences but also action at the community-, clinic-, and health policy-levels.
- Analyzing health inequities through a multi-level, public health framework provides a foundation for more robust and comprehensive approaches to improving population health.
- Implementation science frameworks can be useful at identifying possible avenues for action and key stakeholders.

QUESTIONS?

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