Building a REPAIR Project with Your Community – An Implementation Primer

Jason E. Glenn, Ph.D.
Associate Professor
Department of History and Philosophy of Medicine
1. Cultivating, propagating and upholding the idea of race as an indicator of biogenetic difference
   a. 18th – 19th century efforts to place religious and natural philosophical theories of race into a discourse of biology

2. Racialization of standard allopathic medical practice
   a. Generation of racialized biomedical knowledge
   b. Race “corrections” in clinical algorithmic decision-making
   c. Bias in the clinical encounter

3. Exploitation and abuse of racialized “Others” in the production of biomedical knowledge
   a. Experimentation on slaves
   b. On prisoners
   c. On poor people of color
   d. On poor people from other countries

4. The mechanisms by which structural racism impacts clinical care
“The Racialization of medical thinking is the process that translates the racial folklore circulating in the larger society into a medical doctrine of perceived (and usually imaginary) racial differences.”

John Hoberman, *Black and Blue: The Origins and Consequences of Medical Racism*
Racialization in Medicine at Work

Racialization has all the following impacts on our lives:

1. Pervasive socially and structurally-determined health inequities.
2. Lack of universal healthcare
3. High and increasing infant and maternal mortality rates
How do we repair the harms caused by centuries of neglect, exploitation and abuse in clinical encounters, and by biomedical systems of knowledge that have justified this mistreatment of POC by propagating and upholding theories of race, racial difference, and racial inferiority?
REPAIR = Theoretical framework for coordinating institutional trainings, community collaboration and anti-racism curriculum throughout the university.

The National REPAIR Network
**Institutional Buy-in: Leadership Team**

**Implementation Committee:**
- Jerrihlyn McGee  
  (Vice Chancellor for DEI; Clinical Assistant Professor, SON)
- Carrie Francis  
  (Associate Dean, Workforce Innovation and Empowerment, Faculty Affairs & Development; Otolaryngology, Head and Neck Surgery)
- Margaret Smith  
  (Associate Dean, Office of Diversity and Inclusion, SOM; Family Medicine and Community Health)
- Joe Fontes  
  (Assistant Dean of Foundational Sciences, Office of Medical Education; Department of Biochemistry and Molecular Biology)
- Leslee Taylor  
  (Vice Chair, Program Director, Physical Therapy and Rehabilitation Science)
- Maria Alonso Luaces  
  (Director, Office of Diversity and Inclusion; Department of Family & Community Medicine [Education Division])
- Danielle Binion  
  (Office of DEI Project Director)
- Jill Peltzer  
  (Associate Professor, SON)
- Erin Corriveau  
  (Associate Professor, Department of Family Medicine and Community Health)
- Kristina Bridges  
  (Assistant Professor, Family Medicine Research)
- Elizabeth Muenks  
  (Assistant Professor, Department of Psychiatry and Behavioral Sciences)
- Scott Moser  
  (Associate Dean of Curriculum, Vice Chair for Education, (SOM) Wichita Campus)
- Olivia Veatch  
  (Assistant Professor, Department of Psychiatry and Behavioral Medicine)
- Julie Galliart  
  (Associate Dean, Faculty Affairs and Development, Wichita)
- Julius Leary  
  (Assistant Dean for Graduate Medical Education – Curriculum)
- Natabhona Mabachi  
  (Director of Evaluation and Research Investigator at the American Academy of Family Physicians)

**Community Reps:**
- Rev. Tony Carter, Guietta Payne, Geri Sanders, Carmaletta Williams, Kim weaver
Institution-Level Theoretical Framework

Institution-wide programs organized around four main pillars of understanding:

**Pillar 1**
- The history of how biomedicine perpetuates racism and reinforces theories of racial difference

**Pillar 2**
- Decolonizing the health sciences from bench to bedside

**Pillar 3**
- Action: Strategies to address structural racism and other isms from a socio-ecological perspective

**Pillar 4**
- Accountability: Envisioning how the field of biomedicine can repair these harms.
<table>
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<th>REPAIR Project Initiatives</th>
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<td><strong>Curriculum Development</strong></td>
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<tr>
<td>• School of Medicine</td>
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<td>• School of Nursing</td>
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<td>• School of Health Professions (TBD)</td>
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<td><strong>Faculty and Staff Training</strong></td>
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<tr>
<td>• History of Systemic Racism in Medicine</td>
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<td>• Structural Competency</td>
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<td>• Implicit Bias</td>
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<td><strong>Clinical Care</strong></td>
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<tr>
<td>• Develop dashboards using the EMR</td>
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<td>• Measure inequities by race, ethnicity, gender and language</td>
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<td>• Targeted educational interventions</td>
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<td><strong>Community Accountability</strong></td>
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<tr>
<td>• Oral History/Photovoice project to identify past harms</td>
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<td>• Community defines how to repair those harms</td>
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Decolonizing Curriculums: Foundations in History

Pillar 1: History of Systemic Racism in Medicine
Why is this important? Bias & isms in content costs us

- structural violence
- structural racism/isms

Biased content
- promotes stereotypes, diminishes empathy

Perpetuates disparities in patient care

Contributing to poor health outcomes & health inequities

Structural vulnerability
Curriculum Development Team

**Year 1: History, Structures and Health**

**Goal:** To build historical understanding and a shared language around structures that promote inequity, their effects on health, and frameworks for exploring health outcomes.

- Understand the history of systemic racism in biomedicine
- Identify structures that promote inequities and understand their influence on health and the provision of care.
- Define structural violence and structural vulnerability and identify how they influence health outcomes and care
- Identify the processes through which inequality is naturalized and examine three implicit frameworks: culture/stereotypes, individual implicit bias, institutional bias.

**Year 2: Structural Competency Framework**

**Goal:** To adopt a structural competency framework as a tool to unveil the influences of structures that promote inequity on patient health and healthcare practice

- Understand and use the structural competency framework to recognize and respond to health and illness as the downstream effects of broad social, political, and economic structures.
- Provide health care professionals with the concepts and vocabulary necessary to fully engage in informed conversations and advocacy around structural violence and vulnerability.

**Year 3 and Year 4: Identifying and Imagining Structural Interventions**

**Goal:** To be able to identify and use tools that help practitioners take action to address health and illness as the downstream effects of broad social, political, and economic structures.

- To identify six levels of intervention that we can use to recognize and implement action steps that respond to structural violence, structural vulnerability, and the naturalization of inequality.
- To describe at least one historical and/or contemporary national or local example of an intervention that addressed structural violence and vulnerability.
Write new set of objectives for Diversity, Health Equity and Inclusion aligned with REPAIR Project pillars.

Identify and remove all instances where race is used as proxy for biogenetic difference.

Examine all PBL cases for missed opportunities to teach about social and structural determinants of health.

Rewrite PBL cases aligned with new DHEI objectives, where considerations of SSDoH are regularly a part of diagnostic thinking and treatment considerations.

Assessment of learners and evaluation of implementation.
Faculty Development

Pillar 2: Decolonizing the Health Sciences
Lessons learned

• Students continue to see missed opportunities & long for meaningful integration across the whole curriculum

• Inclination by faculty to strip or “whitewash” content rather than make change

• Faculty have knowledge gaps & general discomfort with concepts and ideas around bias, race/racism, structural competency, structural racism/isms

• Faculty concerns about workload/time, being judged (by students & peers), content becoming less rich

• Faculty appreciated scaffolded nature of intervention (INFORMATION, REFLECTION, ENACTION)
ANTIRACISM BOOK CLUB
2019 - 2023

Kristina Bridges, Ph.D.
(Department of Family Medicine, Research)

Jason Glenn, Ph.D.
(Department of History and Philosophy of Medicine)

UNIVERSITY OF KANSAS MEDICAL CENTER
COMMUNITY CONVERSATIONS
TURNING THE PAGE
A discussion of books about systemic racism and its impact on health care, bio-medical research and health disparities in America.
Led by Kristina Bridges, Ph.D.

1st THURSDAYS, 12-12:45 P.M.
HR CONFERENCE ROOM (1051 WESCOE)
Light refreshments served. Please feel free to come and go as your schedule allows.
All sessions available through Zoom.

SEPTEMBER 5, 2019
"White Fragility: Why it's So Hard for White People to Talk About Racism"
Robin DiAngelo

OCTOBER 3, 2019
"Battling over Birth: Black Women and the Maternal Health Care Crisis"
Julie Changwe Oparah, Helen Arene, Danaita Hudson, Linda Jones & Taela Osagwara

NOVEMBER 7, 2019
"Stamped from the Beginning: The Definitive History of Racist Ideas in America"
Ibram X. Kendi

DECEMBER 5, 2019
"Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present"
Harriet Washington

FEBRUARY 6, 2020
"Just Medicine: A Cure for Racial Inequality in American Health Care"
Dayna Bowen Matthew

MARCH 5, 2020
"Borderlands/La Frontera: The New Mestiza"
Gloria E. Anzaldúa

APRIL 2, 2020
"Between the World and Me"
Ta-Nehisi Coates

MAY 7, 2020
You, me and them: Experiencing Discrimination in America
NPR special series

FOR MORE INFORMATION
For more information: Alexis Smith, 913.584.1480 or asmith@ku.edu

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Diversity and Inclusion Cabinet Programming, Student Affairs, Counseling and Educational Support, Department of Family Medicine, Department of Research, Office of International Programs, Student Life, KU Medical Center, The University of Kansas
Anti-Racism Book Club

Community Conversations

Short documentary - conversation with the filmmakers
IMPLICIT/UNCONSCIOUS BIAS

Newly developed training at KUMC improves on the Cook-Ross© training previously offered to focus more on structural determinants.

Two-hour sessions offered monthly and open to all

Advertised via broadcast emails, DEI website, institution calendar, and new employee orientation

CE credit offered (free for KUMC and TUKHS)

From 2018-2020, 1,408 employees currently around 2,500

Post evaluation on RedCap, 923
Goal: deconstruct and de-naturalize the idea of race for an increased understanding of the systemic nature of racism and how it impacts health

• The Birth of Race: Genocide of Indigenous Peoples & Colonization of the Americas (Jason Glenn, History of Medicine)
• The Transatlantic Slave Trade and the Evolution of Racial Thinking (Jason Glenn, History of Medicine)
• The Civil War and Reconstruction (David Roediger, Dept. of History, KU Lawrence)
• The Jim Crow Era (Kristina Bridges, Family Medicine, and Shawn Leigh Alexander, Chair, African and African American Studies)
• The Civil Rights Movement (Jason Glenn and Kristina Bridges)
• Stress and Allostatic Load (Jill Peltzer, School of Nursing; Kakra Boye-Doe)
SIX-PART EDUCATIONAL SERIES

- 75-minute sessions with a follow up debrief
- CE credit offered (free for KUMC) at a nominal cost of $60 for non-KUMC and TUKHS
- 675 participants (113 average per session)
- Pre-poll within zoom and post evaluation on RedCap
  - Trended higher in last session and post-poll
  - Room for improvement in Q2 and Q3
SIX-PART EDUCATIONAL SERIES

GROUNDING

Pillar 1: The history of how biomedicine perpetuates racism and reinforces theories of racial difference

• Series Objectives:
  1. Describe and discuss race as a social construct versus race as a genetic factor
  2. Describe and discuss: Decolonization of health sciences and health care
  3. Describe and discuss: The history of systemic racism and structural violence from a socio-ecological perspective.
  4. Describe and discuss: Reconciliation and repair in biomedicine.

• Pillar 2: Decolonizing the Health Sciences from bench to bedside

• Pillar 3: Action - Strategies to address structural racism and other isms from a socio-ecological perspective

• Pillar 4: Accountability - Envisioning how the field of biomedicine can repair these harms.
EVALUATING THE SIX-PART EDUCATIONAL SERIES

Q1. I can describe and discuss: Race as a social construct versus race as a genetic factor

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Q3. I can describe and discuss: The history of systemic racism and structural violence from a socio-ecological perspective

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EVALUATING THE SIX-PART EDUCATIONAL SERIES

Q2. I can describe and discuss: Decolonization of health sciences and health care

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

n=92    n=46    n=44    n=39    n=35    n=41    n=77
EVALUATING THE SIX-PART EDUCATIONAL SERIES

Q4. I can describe and discuss: Reconciliation and repair in biomedicine

n=92  n=46  n=44  n=39  n=35  n=41  n=77
Clinical Interventions: Health Equity Accountability Dashboards

Pillar 3: Action Strategies
Step 1: Review Health Inequity Literature for all Clinical Fields

Trends of Racial/Ethnic Differences in Emergency Department Care Outcomes Among Adults in the United States From 2005 to 2016
Xingyu Zhang 1, Maria Carabello 2, Tyler Hill 3, Sue Anne Bell 1, Rob Stephenson 1, Prashant Mahajan 4

Impact of site of care, race, and Hispanic ethnicity on medication use for childhood asthma
Alexander N Ortega 5, Peter J Gergen, A David Paltiel, Howard Bauchner, Kathleen D Belanger, Brian P Leaderer

African–American Prostate Cancer Disparities
Zachary L Smith 5, Scott E Eggener 2, Adam B Murphy 3

Racial and ethnic disparities in the management of acute pain in US emergency departments: Meta-analysis and systematic review
Paulyne Lee 7, Maxine Le Saux 3, Rebecca Siegel 2, Monika Goyal 4, Chen Chen 5, Yan Ma 6, Andrew C Meltzer 7

Racial/Ethnic Disparities in Neonatal Intensive Care: A Systematic Review
Krista Sigurdson 7, 8, Briana Mitchell 4, 9, Jessica Liu 4, 9, Christine Morton 9, Jeffrey B Gould 6, 10, Henry C Lee 4, 9, Nicole Capdarpest-Arest 8, Jochen Probst 4, 3

Variation in hospital discharges for ambulatory care-sensitive conditions among children
J D Parker 1, K C Schoendorf

Racial and ethnic differences in time to acute reperfusion therapy for patients hospitalized with myocardial infarction
Elizabeth H Bradley 1, Jeph Herrin, Yongfei Wang, Robert L McNamara, Tashonna R Webster, David J Magid, Martha Blaney, Eric D Peterson, John G Canto, Charles V Pollack Jr, Harlan M Krumholz
### Health Outcomes
- Maternal and Infant health
- Cardiovascular disease
- Metabolic diseases
- Asthma
- Cancer
- Kidney disease
- Liver disease
- Organ Transplant

### Process Outcomes
- Door-to-drug /procedure times
- Screening and referral rates for asthma, cancer, diabetes
- Pain assessment and management decisions
- Prescription decisions
- Screening, diagnosis, management of disease
- Surgery referrals
Step 3: Prioritize CEIs (Critical Equity Indicators)

- Collaborate with Community to Prioritize top five critical equity indicators (CEIs) in each field
- Identify measures with the greatest disparity across race, ethnicity, and language, for each department
- Inequities of top community priority will be implemented into a dashboard
• Heath Equity Extraction Data (HEED) App
• Data Modeling tool built into KUMC REDCap - secure web application for building databases
• Healthcare Enterprise Repository for Ontological Narration (HERON)
• Translated outcomes from literature search into EHR codes
• Analyze system-wide health equity performance for clinical departments at KUMC
Implementation

Consult
Consult with clinicians and medical informatics to refine health equity indicators and coding within the EMR

Collect
Collect health equity data for all clinical departments at KUMC – 5 years back and 5 years forward

Analyze
Analyze the data according to race, ethnicity, gender, and language as available in the EMR

Compile
Compile data into a health equity accountability dashboard for each department

Implement
Implement evidenced-based interventions (QI framework, targeted education, action-focused structural competency training)
Envisioning Racism and Repair

Pillar 4: Community Accountability
Engage the KC community in an oral history project to better understand the individual, family, and community harm caused by racism and identify what we need to repair.

1) What are the harms that local community members carry with them?
2) What are their inherited memories and lived experiences of harm at the hands of biomedicine?
3) What restorative actions would it take to repair those harms?
4) How should KUMC and other area institutions work with communities to design and implement its restorative work?
Methods: Oral History and Photovoice
Interdisciplinary Team

Community Partners
Reverend Tony Carter
Ms. Evelyn Cooper
Ms. Geri Sanders
Ms. Kim Weaver

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<thead>
<tr>
<th>Discipline</th>
<th>Lead PI/Co-PI</th>
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<tr>
<td>History of Medicine</td>
<td>Dr. Jason Glenn (PI)</td>
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<tr>
<td>Nursing</td>
<td>Dr. Jill Peltzer (Co-PI)</td>
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<tr>
<td>Health Communications</td>
<td>Dr. Crystal Lumpkins (Co-PI)</td>
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<tr>
<td>Black Archives of Mid America</td>
<td>Dr. Carmela Williams (Co-PI)</td>
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<tr>
<td>Social Work</td>
<td>Ms. Kortney Carr (Co-I)</td>
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<tr>
<td>Office for DEI</td>
<td>Ms. Danielle Binion</td>
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Part 1: Community Listening Sessions

• 15 small groups of ten participants
• Held at community centers, churches, & other community spaces
• Moderated by a trained community partner using an Interview Guide designed in a trauma-informed care format and a researcher
Part 2: Individual Interviews

- Identify 30 individuals with the most salient stories
- Part 2A: One-on-one recorded interview @ Black Archives.
  - Give photovoice assignment: 10 – 15 photos that represent past harms and repair.
- Part 2B: Return for second interview to narrate photos taken.
Next Steps

Analyse

Oral histories will be analyzed using thematic analysis for themes that cross all narratives

Validate

Validate results with the community

Deliberate

Host Community Action Labs to define what repair should look like

Develop

Develop Report with recommendations for Institution

Curate

Curate Oral History Project at the Black Archives of Mid-America

Truth

Host a “truth and reconciliation”-style event where community members present findings to mayor, city council, and university leadership.
Preliminary Findings
“Just listen. Listen to us when we tell you that something is wrong with us.”

• Many participants reported that when they go to the doctor, medical professionals assume that they are not intelligent enough to know what, if anything, is wrong with them.

• Consequently, they do not do a thorough history/assessment or order all necessary lab work to make an accurate diagnosis.

• Instead, assumptions are made based on racial profiling, e.g., assuming the patient is suffering from diabetes, hypertension, an STI/pregnancy, or is drug seeking and not really suffering at all.

• As a result, they prescribe medications or recommend procedures based on these assumptions.
“Don’t just treat my symptoms, care enough to find out what’s wrong with me.”

- Many participants reported that going to the doctor is a constant struggle to be seen and treated as if their lives mattered.
- Participants report needing to pay special attention to their dress, their speech, and overall demeanor in order to be treated like “someone worth saving.”
- Many participants are haunted by memories of loved ones who died too young because they feel like medical professionals did not treat them as if their life was worth saving.
Black women are at least twice as likely to have their uterus removed compared to white women.

- Black women report that healthcare providers are overly eager to give them hysterectomies, even for benign conditions where one is not warranted.

- One participant was subjected to a hysterectomy when she was pregnant, and her healthcare provider did not bother to give her a pregnancy test before the procedure.

- She was told offhand by a nurse afterward, “By the way, it turns out you were pregnant when we took your uterus out.”
“I believe that in a university setting there should be classes taught on what different cultures have had to go through in medical history.”

- Participants voiced that all health professions curricula should include a required course that explores local histories of medical mistreatment as the primary method to prevent future healthcare providers from replicating these harms.

- Participants also advocated for courses to be structured in a way that centers the voices of marginalized groups where students learned from the community—flipping the classroom and challenging power differentials that perpetuate antiquated models of person-provider relationships.
“I breathe a sigh of relief whenever my doctor is Black.”

- More African American doctors, more Black nurses, and more Black patient advocates.
- Wanted Black patient advocates who are able to help navigate the clinical encounter, especially when dealing with a chronic and/or life-threatening illness.
- With respect to the dire situation of maternal and fetal health outcomes, participants said they wanted to see more Black doulas and midwives.