CMSS
COUNCIL OF MEDICAL SPECIALTY SOCIETIES

ENCODING EQUITY
in Clinical Research & Practice
RETHINKING RACE IN CLINICAL ALGORITHMS

# ENCODING EQUITY IMPLEMENTATION TOOLKIT: **CLINICAL AND SPECIALTY SOCIETIES**

# INTRODUCTION

The Encoding Equity Alliance is an alliance of organizations and individuals committed to driving change in clinical research and practice to advance health equity and optimize access and outcomes for all populations. Encoding Equity galvanizes collective action to amplify our impact, making change more quickly and comprehensively than would be possible for any one organization or group of constituencies on their own. Led by the Council of Medical Specialty Societies (CMSS), with support from the Doris Duke Foundation (DDF), the alliance engages and activates individuals and organizations across the medical, research, funding, publishing, and technology sectors.

The ultimate goal of these efforts is to advance health equity through a scientifically rigorous, evidence-driven, context-specific evaluation of the use and misuse of race and ethnicity in healthcare predictive algorithms and guidelines.

## WHY IS THIS IMPORTANT?

There is an ongoing, nuanced debate among healthcare researchers, developers of guidelines and predictive algorithms (i.e., risk modeling), and populations who are affected by these guidelines and algorithms concerning whether and when it is appropriate to include race and ethnicity as model inputs or as driving factors for clinical decision-making.

Race and ethnicity are primarily social constructs and have been used in healthcare research as proxies for a variety of factors for which precise data may not be available. These factors include, socioeconomic status, environmental exposures, epigenetic changes (related to stress, nutritional deficiency, or toxic exposures), genetic ancestry, and the effects of racism and discrimination or their combination. For any specific application of race or ethnicity in healthcare research and predictive modeling, the extent to which race reflects any or all of these factors is variable. Further, while racial and ethnic categories may have considerable overlap with continental genetic ancestry, the latter is continuously distributed rather than categorically, and within-race genetic ancestry is heterogeneous.

The challenge for guideline and clinical algorithm developers is to employ approaches to the use of race and ethnicity that avoid biological determinism or race essentialism (which attribute most between-population differences in health outcomes to biology rather than to social forces), while also recognizing that racial categories often overlap with genetic ancestry and the latter may sometimes be associated with biologic differences that impact disease prevalences or healthcare outcomes. Short- and long-term outcomes are worse, on average, for historically vulnerable, marginalized populations, likely reflecting varying effects of the many factors for which race is a proxy. As more specific social and genetic markers become available for most patients, they will be substituted in place of race and ethnicity, which are imperfect, temporary proxies.

Many professional societies and other organizations that offer clinical guidance and scientific oversight have been reevaluating the use of race in clinical practice, using a variety of approaches. These have ranged from complete elimination of race or ethnicity in specific guidelines or algorithms, to their selective, context-dependent, scientifically supported retention or modification. Complete conceptual and methodological transparency is essential in making these decisions. In each case, the goal is always to reduce health outcome inequities and to promote optimal outcomes for all populations.

While some organizations have begun scientifically rigorous, objective audits of current clinical guidelines and algorithms, coordinated and sustained action and collaboration across the research and clinical communities are required to drive comprehensive change. This resource is informed by and builds on this important foundational work to support the broader movement toward more equitable, evidence-based clinical practice. Findings from the trailblazing work of our Organizations in Action are the building blocks to develop this robust tool, the Encoding Equity Implementation Toolkit: Clinical and Specialty Societies.

## WHAT IS AN IMPLEMENTATION TOOLKIT?

The Encoding Equity Implementation Toolkit: Clinical and Specialty Societies is a tool to support the adoption of practices that explicitly recognize how the use or misuse of race and ethnicity may help, harm, or have a neutral effect on health outcomes for minority populations. This guide is not a step-by-step roadmap but rather a menu of options that any professional society, regardless of stage, size, or specialty, can implement to reduce bias in guidance documents and practice.

There are numerous strategies outlined in this tool, none of which must happen linearly. Organizations may find themselves at different stages of the process and may start and progress throughout this work non-sequentially. Users of this toolkit are encouraged to choose a sensible starting point in the context of their organization. Incremental changes are necessary to advance in this work. Further, there is not a one size fits all approach to mitigating harm and bias in medicine and research, though we hope your organization can identify with the broad strategies outlined in this resource

This toolkit is a compilation of best practices and change-specific strategies, modeled after the Institute for Healthcare Improvement's (IHI) change package framework. The content is divided into the following fundamental components, defined by IHI as:

- **Primary Drivers:** Major processes, operating rules, or structures that will contribute to moving toward the aim.
- **Change Concepts:** Broad concepts (e.g., "Provide strong leadership support for targeted task forces") that are not yet specific enough to be actionable but that will be used to generate specific ideas for change.
- **Change Ideas:** Actionable, specific ideas for changing a process. Change ideas can come from research, best practices, or from other organizations that have recognized a problem and have demonstrated improvement on a specific issue related to that problem.

We recommend piloting the recommendations in this toolkit on a small scale before expanding them across your entire organization. Organizations without the bandwidth or resources to implement this broadly across their society may choose to support individual investigators through grant mechanisms or staff support. These strategies can enable professional societies to take steps toward advancing health equity in guidelines and algorithms.

# CONTENTS

## PRIMARY DRIVER 1: ORGANIZATIONAL COMMITMENT

| Change Concept | Change Idea |
|---|---|
| **Provide strong leadership support** | Executive staff and board members must demonstrate strong leadership commitment to the scientifically rigorous review of race and ethnicity in their predictive algorithms and guidelines, and provide support for those conducting these reviews<br>Examples may include:<br>• Distribute a professional society leadership statement to members describing the rationale for these reviews<br>• Highlight recommendations from the NASEM report (Rethinking Race and Ethnicity in Biomedical Research) and similar, widely respected publications[1]<br>• Establish a task force or working group to conduct these reviews; secure adequate financial, technical, and personnel resources, including society members with content expertise<br>• Encourage diverse, balanced perspectives, including individuals willing to ask difficult questions and challenge longstanding but problematic assumptions<br>• Provide frequent opportunities for task forces to present their progress and challenges to Executive Committees and Boards of Directors |
| | Identify accountable organizational champions or sponsors to drive and complete an audit and systematic evidence review of existing society guidelines and algorithms.<br>• Consider appropriate organizational governance structure, including senior leadership, to support this work (e.g., establishment of a Board Committee, accountable executive role)<br>• Identify respected society members with content expertise who can lead these efforts |

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| **Provide strong leadership support** (cont.) | Anticipate and mitigate internal/external pressures and criticism<br>Examples may include:<br>• Coordinate with society/organizational press offices to convey consistent and judicious messaging regarding project goals and scientific rigor<br>• Remind Task Force members that discussions regarding these topics are often sensitive and highly nuanced, and confidentiality is essential until reports are near completion<br>• Task Force members should solicit advice and support from society leadership regarding particularly controversial issues<br>• Limit external access to Task Force members to avoid pressures from advocacy groups<br>• Ensure staff support (including but not limited to senior executives and communications staff) who can respond to external pressures and serve as a buffer |
| **Build momentum for evaluating the use of race and ethnicity in clinical algorithms and guidelines** | Ground the work in rigorous science and research, always prioritizing optimal quality of care and safety for all patients |
| | Anticipate organizational inertia, the reluctance among society staff and members to reassess or potentially modify well-established algorithms and guidance documents |
| | Start with critical mass of executive and board-level leadership, build support over time |
| | Establish hard deadlines, but allow adequate time to work through the aims of the systematic audit, as the information is evolving and requires flexibility |
| | Use case examples and patient narratives to build support for the guidance audit; place your tailored work within the context of the need you are addressing, and keep up with the evolving science |
| | Share success stories from other organizations to garner support and prove feasibility (e.g., AAP, ATS, ASN, ASH) |

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| **Build momentum for evaluating the use of race and ethnicity in clinical algorithms and guidelines** (cont.) | Develop communication strategies (Driver 4) to manage potential criticism |
| | Develop strategies to maintain momentum and adapt to mid-course corrections |
| | Assess any evidence gaps that may limit progress in advancing this work |
| | Exploit society grant mechanisms for investigators to conduct research in this area |
| **Resource Allocation** | Dedicate adequate staff and other resources to support the expected effort (i.e., number of guidelines or algorithms under consideration). Staff support may include:<br>• Accountable management-level staff lead<br>• Administrative and/or project management staff<br>• Communication staff |
| | Start with a manageable scope (e.g., targeted review of select algorithms, guidance, and related efforts) and expand scope over time (full audit of all active guidelines; see Driver 2) |
| | Ensure organizational investment in internal and external marketing and communication support |
| | Identify external resources, including grants, to support the society work and incentivize task force participation by volunteer leaders |

## PRIMARY DRIVER 2: EXECUTING AN AUDIT OF ALGORITHMS, GUIDANCE, AND RELATED PROCESSES

| Change Concept | Change Idea |
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| **Task Force Participants** | Select a diverse, multidisciplinary group of thought leaders and content experts to serve on the audit Task Force, ideally including but not limited to:<br>• Multi-specialty Physicians<br>• Health Policy and Health Quality Researchers<br>• Epidemiologists<br>• Sociologists<br>• Health Equity Experts<br>• Population Geneticists<br>• Patient Representatives<br>These individuals may participate in one or multiple parts of this Driver, depending on applicability. |
| | Aim for multi-domain diversity in Task Force composition (e.g., seniority, geographic location, specialty and practice type, scientific background, demographics, patient populations served). Prioritize the ability to thoughtfully and rigorously address difficult questions. |
| | Develop and share strategies to include patient participation in society task forces. |
| | Consider open forums where key constituencies (including patients and trainees) can present directly to the task force (e.g., CMSS/PLRC patient-led scorecards[2]) |
| | Consider partnership opportunities with patient groups and voluntary health organizations |

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| **Evaluate Existing Practices** | Conduct an internal audit of existing algorithms, guidance, and guidelines, and the development processes for each[3,4] |
| | Systematically evaluate how race and ethnicity has been used, applying published recommendations from the NASEM report[1] and similar respected documents[5] including, but not limited to:<br>• Identification of relevant historical or social context affecting the clinical condition<br>• Documentation of a principled scientific rationale for use or non-use of race or ethnicity<br>• Assessment of algorithmic fairness issues and trade-offs |
| **Identify Potentially Problematic Areas** | Each algorithm or guideline may have unique considerations that warrant revision, such as fidelity to the original intent of the document; evidence base; impact on equity; inclusion of other social or biological risk factors with or instead of race and ethnicity; applicability in minority populations (e.g., model calibration, potential benefits and harms); and bias assessment. |
| | Algorithms may warrant scrutiny in terms of data sources, representation, validation techniques, and methods to track disparities that arise after deployment |
| | After identifying specific guidelines and algorithms that warrant prioritized reassessment or revision based on evidence of harm to specific populations, consider conducting original research to identify alternative, more specific and appropriate substitutes for race and ethnicity, and how these revisions would be implemented |
| | Assess whether the society's guideline and/or algorithm development processes also warrant proactive revision to ensure a scientifically rigorous and equitable approach[6,7] |

## PRIMARY DRIVER 3: IMPLEMENTATION OF REVISED GUIDANCE OR ALGORITHMS; NEW METHODS TO PROMOTE HEALTH EQUITY

| Change Concept | Change Idea |
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| **Implementing Revised Clinical Algorithms and Guidelines** | Develop materials for clinician and patient education, including the scientific rationale for any changes (e.g., elimination of race or substitution of another variable), available implementation resources (e.g., societal registry data), and any additional system changes required for implementation of the updated algorithms or guidelines |
| | Assess the impact of updated clinical guidance on resource needs (e.g., cost, technology, EMR, coding) |
| | Start small and pilot implementation in focused projects to test impact and needs (resources, cost, staff), thereby informing a more comprehensive implementation strategy |
| | Engage and collaborate with key partners early in the implementation process, including but not limited to other national professional societies; industry; legal, ethics, marketing, IT, and communication consultants |
| **Proactively Adopt and Utilize Approaches that will Promote Health Equity in Future Algorithms and Guidelines** | In the development of all future guidelines and algorithms, systematically and rigorously evaluate the use of race and ethnicity throughout the research and evidence review process, preferably based on recommendations from the NASEM report[1] and other similarly respected publications |

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| **Proactively Adopt and Utilize Approaches that will Promote Health Equity in Future Algorithms and Guidelines** (cont.) | For **guidelines and guidance** documents, use/reference existing guidance to help promote incorporating health equity into guideline development[8], which may include:<br>• Pre-specify populations of interest with an explicit rationale (e.g., differences due to heritable risk versus social risk with biological consequences)<br>• Incorporate upstream drivers of racial health inequities as well as equity relevant populations, outcomes, and settings in conceptual models<br>• Integrate a broader set of questions, beyond effectiveness and harms, which may include: addressing upstream determinants and implementation considerations (e.g., availability, feasibility, cost, quality, patient acceptability) in developing recommendations<br>• Evaluate the representativeness, rigor, and applicability of the evidence base<br>• Evaluate differences in absolute effects of benefits and harms across racial and ethnic populations<br>• Identify equity-specific evidence gaps<br>• Articulate relevant question(s) on implementation considerations affecting racial health inequities<br>• Articulate equity-relevant clinical practice and policy gaps during the guideline or decision-making process |
| | For algorithms, develop or adopt a checklist for the algorithm development team to promote health equity in the algorithm-implementation lifecycle, with the following key considerations[9,10]:<br>• Dataset fidelity<br>• Use of diverse and representative data to minimize inherent biases<br>• Algorithm development and validation using fairness constraints to promote equitable outcomes[11] |

## PRIMARY DRIVER 4: COMMUNICATION

| Change Concept | Change Idea |
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| **Organizational Communication and Socialization** | Ensure that leaders and staff understand and can effectively and accurately communicate the scientific and health policy rationales for this work |
| | Provide support and time for task force members and staff to process the sensitive nature of reviewing bias in previous work |
| | Support leaders and staff who may receive positive and negative feedback or responses to the project from membership or the general public |
| | Recognize complexity, context specificity, nuance, and uncertainty as inherent features of this process; maintain humility and curiosity |
| | Create opportunities for shared learning |
| | Incorporate opportunity for society membership and external stakeholder feedback, including transparency around the comments received and how feedback was implemented |
| **Strategic Messaging** | Communicate recommended changes to algorithms and guidelines with robust scientific evidence that can withstand public scrutiny |
| | Consistently communicate the project’s key message and goals: Promotion of optimal care and outcomes for all populations, using evidence-based, scientifically rigorous, nuanced, and context-dependent approaches |
| | Work with other organizations to build a joint communication working group, incorporating lessons and strategies learned by each organization |
| | Publish in peer-reviewed journals and responsible, trustworthy lay press articles |

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| **Engage Constituencies** | Identify trusted authorities to communicate your work; ensure that they consent to publicly sharing their name, photo, and any other necessary information |
| | Identify target audiences for any updated algorithms or guidelines, including physician members of the relevant society; other specialty societies and their members; other clinicians; health systems and hospitals; researchers, health policy experts, epidemiologists and statisticians; technology partners; funders; patients and advocates; and the media |
| | Develop customized messages and materials (e.g., clinician and patient education materials, toolkits, micro-learning via social media, educational conferences, or scientific co-learning sessions at other societies) for specific target audiences that facilitate implementation of updated algorithms and guidelines<br>• In clinical education, include guidance on how to explain to affected patients any changes in care that result from updated guidelines or algorithms; respond to their concerns, if any<br>• Ensure that a diverse group of patient and/or care partner representatives are involved in the development of patient education materials |
| | Amplify messaging by collaborating with project partners when communicating findings and updates to recommendations |
| | Pilot a variety of communication approaches |
| | Implement communication strategies for dealing with misinformation, pushback, and difficult questions |

# ACRONYMS

**AAP:** American Academy of Pediatrics

**ASH:** American Society of Hematology

**ATS:** American Thoracic Society

**ASN:** American Society of Nephrology

**CMSS:** Council of Medical Specialty Societies

**DDF:** Doris Duke Foundation

**EMR:** Electronic Medical Record

**IHI:** Institute for Healthcare Improvement

**IT:** Information Technology

**NASEM:** National Academies of Sciences, Engineering, and Medicine

**PLRC:** Patient-Led Research Collaborative

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