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Letter to NLM about MeSH

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Dear MeSH Committee.

We, a group of medical library workers, are reaching out to request changes be made to the process in which medical subject headings (MeSH) terms relating to marginalized groups (based on but not limited to race, dis/ability status, ethnicity, sexual orientation) are decided upon in order to make them reflective of practices that use person-first language, recognize the problematic nature of outdated and offensive terms, and take into account the identifiers used by the communities themselves, while also making them inclusive and respectful of the groups being described in order to not cause harm.

Specifically, we are asking that this process be transparent and open to feedback from information professionals, researchers, scholars, and the communities whose lived experience are most impacted by these terms, as we are all stakeholders who use PubMed and benefit from the research and scholarship made available through this resource.

We request that you address the MeSH vocabulary, which is outdated, discriminatory, and includes offensive terminology making up its controlled vocabulary and scope notes. We and other medical library workers have experienced consistent road blocks and a lack of information in response to concerns brought forth related to the MeSH vocabulary, we now provide you the opportunity to address the following concerns:

MeSH Record: "Blacks"

A more recent incident is the introduction of the <u>MeSH term "Blacks"</u> that was previously noted as the "African Continental Ancestry Group." The use of this terminology is not only concerning for information professionals, but creates great harm for our users as well as those in the profession. "Black" as a term used to denote racial identity is a proper adjective; not a noun. Here's <u>guidance that the Journal of the American Medical Association (JAMA)</u> (Flanagin et al., 2021) has published and a <u>New York Times article</u> that gives further context.

As in the past, when library workers reached out through emails and submission forms to the MeSH Committee to ask that this terminology be changed, they were met with a lack of any thoughtful response or indication that the committee understood the trauma such terminology would inflict. The responses, when they were not just an acknowledgement that the request was received, most times felt scripted and did not answer the concerns being addressed.

In addition, the scope note needs revision as well. Recommending that the outdated term "Negro" be used is not acceptable, especially not in 2022¹, and this was a missed opportunity to write a respectful definition in the scope note as opposed to simply listing discoverable terms lacking necessary context. Utilizing cultural humility in the creation of scope notes would assist in making these both discoverable and respectful. Please take a look at <u>Cultural Humility as a Framework for Anti-Oppressive Archival Description</u> (Tai 2021) and <u>Queering the Catalog:</u> <u>Queer Theory and the Politics of Correction</u> (Drabinksi 2013) for recommendations on how to accomplish this.

¹ APA Inclusive Language Guidelines

We are asking that this committee reverses the unnecessary harm that they have already caused and minimizes further unnecessary harm or trauma by taking the following actionable steps: :

- 1. Immediately updating the MeSH "Blacks" to an appropriate and correct term (e.g. "Black people") and including a definition in the scoping note that accurately represents the identities of those being attached to the subject heading. It is also important to recognize that selecting terminology to describe a racial group is a very nuanced issue, as there is no one global term for individuals of the African Diaspora. Individuals may identify as Black, African American, or by their country of origin.
- Update scope notes of race-specific terms to inform PubMed users that race is socially constructed and is not considered a biological concept, but rather as a proxy to investigate social and health disparities. Consider adding this language to the following MeSH records
 - a. Racial Groups and branch terms

MeSH Review and Decision-making Process

Below are recommendations to make further improvements to the MeSH creation, review, and decision-making process.

Build in more transparency

- 3. Creating transparency in the process of editing/updating/creating MeSH by:
 - a. Documenting the review process, who is involved in the creation of MeSH and what makes them subject experts able to address such topics, how decisions about MeSH changes are made, and supplying open access to these documents
 - b. Providing transparency and also assessing for bias of any algorithmic-based decision making in adding new terms or indexing them to PubMed records

Bring in experts and pay for their labor

4. Bringing in appropriate experts at early stages of the review process to discuss improvements to identity-based MeSH terms and pay them for their labor and expertise – whether this be through hiring consultants or engaging with information professionals, researchers/scholars, and community leaders who have expertise in addition to lived experience

Create avenues for feedback

5. Creating processes when reviewing and updating MeSH that include the public and information professionals at early stages of the review process. This could include town halls, national calls, public forums, and more.

Provide training opportunities

6. Implementing training for all members of this committee that are conducted by outside entities and pay experts for their labor, time, and knowledge.

When searching within MeSH, users should not have to be confronted with derogatory and trauma-inflicting language in order to find articles that can assist with their needs (see Tai 2021 and Drabinski 2013 articles listed above for more information). As the largest freely available biomedical database, PubMed should hold itself to the highest standards of inclusion and interdisciplinary connections on both a national and a global scale as a leader on these issues. Terms like "Blacks" and others that have been identified should not be allowed in such a space and calls for changes from the information professionals utilizing these resources should not go ignored. In addition, maintaining historical records in order to improve discoverability should not come at the cost of creating a hostile environment for users. As current and former medical library workers, it is difficult for us to continue to explain or support NLM's MeSH vocabulary and term changes that are harmful to the students and other researchers that we work with.

Organizing and categorizing information has always been a key responsibility of libraries. The NLM can and should take a leading role in updating terminology in a way that increases access to information without harming others. Other government agencies and departments like the OMB and HHS may also benefit from this important work.

For our part, we intend to work with the Medical Library Association, information professionals, our networks, and other organizations to bring awareness to this issue. We want to ensure that our goal is to bring stakeholders together and advocate for a more inclusive controlled vocabulary benefiting the health of communities we support.

As key stakeholders and users of NLM's information resources, we ask that you will take our requests seriously and we look forward to hearing your response.

For further context behind the asks in this letter, please read the following Twitter threads:

Christian Minter on MeSH terms "Blacks" and "Health Disparity, Minority and Vulnerable Populations":

https://twitter.com/LibGirl09/status/1524804803779608576?s=20&t=2hAPREWEqvJ5KBx3yH9c TA

Aidy Weeks on the history of communicating inclusive MeSH term changes with NLM/NIH, and a call for collective activism and increased communication between MLA and NLM/NIH: https://twitter.com/wonderbrarian/status/1525134374806511617?s=20&t=1E3W5R_C5v2Bql06ndv3SQ

Alissa McCulloch, a cataloguer based in Australia, on the MeSH term "Native Hawaiian or Other Pacific Islander":

https://twitter.com/lissertations/status/1495893166243074051?s=20&t=MH_3qRX_j2jtB7DbE-vq8w

To sign this letter please either fill out this form or email your information by May 31, 2022:

- https://forms.gle/gDbXFyq4ND3s9h4x8
- If you cannot access Google Forms and would like to sign this letter, please send an email as either "anonymous signer" or your name, title, and affiliation to a library association or group, to mlalatinx@gmail.com

To share this letter with others please use this link:

https://docs.google.com/document/d/1DBXX157InIhLcDTWMSQv0mwA6ZkdWL_0Awt6Qa5_Yfc/edit?usp=sharing

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- 276. Hella Bluhm-Stieber, Medical Librarian, County of Santa Clara Health System
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- 278. Natalie Clairoux, Dental Librarian, Université de Montréal
- 279. Margaret Smith, Physical Sciences Librarian, NYU
- 280. Seema Bhakta
- 281. Shawn Steidinger, Clinical Services Librarian, University of Utah, Spencer S. Eccles Health Sciences Library
- 282. Megan De Armond, Touro University Nevada, Systematic Review Services Librarian
- 283. Ash Barber, Support Librarian, University of South Australia
- 284. Alison Forde, E-resources librarian, NHS Scotland
- 285. Keith Nockels, Academic Librarian (medicine and allied health), University of Leicester, UK
- 286. Katrina Hall Medical Librarian, United Kingdom
- 287. Hannah Cochrane, Corporate Librarian, UK.
- 288. Imrana Ghumra Co-Chair health Libraries Group
- 289. Andra Fry, Information Specialist, London School of Economics and Political Science
- 290. Kerri Daymond
- 291. Pauline Goodlad, Librarian, Betsi Cadwaladr University Health Board (Wales, UK)
- 292. Ms Razia Nazir, Knowledge & Library Service Manager
- 293. NicolaTricker (Information Specialist), University of Plymouth, UK
- 294. Cathryn Peppard, Information Skills Manager

- 295. Fiona Bourne, Archive Manager
- 296. Lindsay Snell, Clinical Librarian, University Hospitals of Derby and Burton NHS Foundation Trust, UK
- 297. Ian Clark, Psychology Librarian, University of East London
- 298. Alice Cleaver, Assistant Librarian and LIS student
- 299. Paul Cannon, University of Glasgow Library, Scotland
- 300. Patricia Rey MA BA MCLIP
- 301. Gillian Foster
- 302. Nicola Ager
- 303. Naila Dracup, Evidence and Knowledge Specialist, Rotherham NHS Foundation Trust
- 304. Kirsten Buckley MA, NHS Knowledge Specialist
- 305. Chris Lawton Acting Library & Knowledge Services Manager Northern Lincolnshire & Goole NHS Trust
- 306. Chris Johns, Senior Information Specialist, Plymouth, UK
- 307. Tom Kelly, Sussex Health Knowledge & Libraries, UK
- 308. Kirsty Morrison
- 309. Caroline Lynch, MCLIP, Information Literacy Specialist
- 310. Stephen A Bowman, Medical School Librarian and TEL Lead, University Hospitals Sussex NHS Foundation Trust, UK
- 311. Ms Marina Rossi Information Professional (NHS)
- 312. CJ Taylor
- 313. Nia Wyn Roberts, University of Oxford
- 314. Eli Harriss, University of Oxford
- 315. Farhad Shokraneh, BSc MSc MedLIS, PhD Medicine, Information Scientist at Cochrane Heart, University College London
- 316. Cecilia Bethencourt-Dunning, Librarian, University Hospitals Sussex
- Jill Boland Academic Librarian for Health, Psychology, & Social Care, University of Derby

- 318. Ben Skinner, University Hospitals Sussex NHS Foundation Trust
- 319. Rachel Playforth
- 320. Rachel R Walden, MLIS, Associate Dean, Medical Library Director
- 321. Stephanie Henderson, MLS, MLA Member
- 322. Arthur Robbins Library, Information & Knowledge Services Manager Roche Products Limited
- 323. Tyler Moses, MLS, Medical Librarian
- 324. Jessica Sender, Librarian for the College of Nursing, Michigan State University
- 325. Nina McLaughlin, Library Assistant, University Hospitals Cleveland Medical Center
- 326. Naz Torabi, MLIS, University of Toronto
- 327. Damiana Fortenberry, MLIS, Health Sciences Librarian
- 328. Suzanne Duncan, MSLS Director, Library Services Sentara Healthcare
- 329. John Carter, MLIS, AHIP, Library Associate, NYIT College of Osteopathic Medicine at Arkansas State University
- 330. Giada Zanella, Information Specialist at Aston University
- 331. Amy Dunn, Specialist Librarian
- 332. Jane Kinkus Yatcilla, Associate Professor, Purdue Libraries and School of Information Studies
- 333. Bradley A. Long, Embedded Health Sciences Librarian, Harrell Health Sciences Library, Pennsylvania State University
- 334. Elisabeth Wallace, MSIS, Mountain Area Health Education Center
- 335. Lionel M. Williams, GW/Himmelfarb, Serials Manager
- 336. Katie Birkwood, Rare Books and Special Collections Librarian, Royal College of Physicians
- 337. Laura Abate, Director (interim), Himmelfarb Library, The George Washington University
- 338. Christine Neilson MLIS, University of Manitoba
- 339. Elizabeth Jenkins, Education and Access Services Management Librarian, Boston University Alumni Medical Library

- 340. Carrie Grinstead, Providence
- 341. Shanda Hunt, public health librarian and data curation specialist, University of Minnesota
- 342. Ingrid Francis, NHS Library and Knowledge Specialist, UK
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- 348. Samantha Loster, MSLIS
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- 351. Lindsay Roberts
- 352. Mari Ann Hilliar Subject Librarian Cardiff University
- 353. Lucy Welch, Healthcare Subject Librarian at Cardiff University
- 354. Delyth Morris, Cardiff University
- 355. Mary J. Markland, Director Guin Library, Oregon State University
- 356. Claire Beecroft, University Teacher and Information Specialist, ScHARR, University of Sheffield
- 357. Sue Steele, Library and Knowledge Services Manager
- 358. Heidi Sue Adams, MS Lead Medical Librarian Logan Health Medical Library, Kalispell MT USA
- 359. Alice Stokes, Research and Education Librarian, Dana Medical Library, University of Vermont
- 360. Elizabeth Gillen, Cardiff University
- 361. Ric Paul, Head of Partnerships and Place, University of Southampton Library

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- 364. Isla Kuhn, Head of Medical Library Services, University of Cambridge, United Kingdom
- 365. Melis Lydston, MLS, Librarian Informationist, Treadwell Library, Massachusetts General Hospital
- 366. Alissa V. Fial, MA, MLIS
- 367. Madelena Romansic
- 368. Amy Six-Means, MLIS, Medical Librarian Children's Health
- 369. Ruth Bueter: Serials Librarian, Himmelfarb Health Sciences Library (George Washington University)
- 370. Ian Roberts, Acquisitions and Resource Sharing Librarian, Himmelfarb Health Sciences Library, The George Washington University
- 371. Gina Levitan, First Year Outreach Services Librarian
- 372. Gregg A. Stevens, MSLS, MST, AHIP
- 373. kalan Knudson Davis, Rare and Special Collections Metadata Librarian, University of Minnesota Twin Cities
- 374. Brett Nafziger, Operations Manager Centennial Science & Engineering Library, UNM
- 375. Deborah Goss, MLS, Boston, MA
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- 378. Pamela Pierce, OHSU
- 379. Mark MacEachern, Librarian, University of Michigan
- 380. Andrea Miller-Nesbitt, McGill University Library
- 381. Edith Scarletto, MLIS, Bowling Green State University, Bowling Green, OH
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- 383. Gurpreet K. Rana, MLIS, Global Health Coordinator, Taubman Health Sciences Library, University of Michigan

- 384. Debbie Jan, Emeritus Librarian, UC Berkeley
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- 386. Christiane E. Voisin
- 387. Tyler Nix, Taubman Health Sciences Library, University of Michigan
- 388. Leigh Billings, Metadata Management Librarian, University of Michigan
- 389. Graeme Tierney, Library Assistant, Whittington Health NHS Trust, London UK
- 390. Roman Block, MLS, Oregon Health & Science University
- 391. Diana Nelson Louden, Life Sciences Librarian, University of Washington
- 392. Patricia F. Anderson, Emerging Technologies Informationist at University of Michigan-Ann Arbor, Taubman Health Sciences Library
- 393. Gabriele Hayden, Librarian for Research Data Management and Reproducibility, University of Oregon
- 394. Corinne Petro, Reference Specialist, Himmelfarb Health Sciences Library, George Washington University
- 395. Karina Kletscher, MLIS, Reference and Instruction Librarian, Creighton University
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- 405. Samantha Johnson, Academic Support Librarian (Medicine), University of Warwick
- 406. Lucy Sinclair

- 407. Rosalind Francis, Anglia Ruskin University
- 408. Rachel Sully, NHS Wales e-Library and Knowledge Service Manager
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- 410. Tom Rowland (member of public)
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- 435. David Lightfoot, Information Specialist, Unity Health Toronto
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- 439. Victoria Cole, Research Librarian University of Ottawa, MScN, MIS
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- 450. Anne Cerstvik Nolan. Head, Collection Strategies for Licensing and Assessment, Brown University Library
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- 452. Moses Moya, MLIS Metadata Specialist at University of New Mexico Health Sciences Library
- 453. River Freemont, Student Archives Assistant, Oregon Health & Science University
- 454. Tonya Mahar
- 455. Janice Hermer

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- 480. Sarah C. McGill, Research Information Specialist, BSc MLIS

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- 483. Sandi L. Bates MLIS
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- 493. Mya Ballin, MAS, MLIS
- 494. Dorice Vieira, Curator, NYU Health Science Library
- 495. Mary-Doug Wright, Consulting Information Specialist
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- 497. Andrew Tran, PT, DPT, NCS, CSCS
- 498. Patricia Stott, Librarian, Eastern Health Library Service, Melbourne, Australia
- 499. Candise Branum, Health Science Librarian, Gonzaga University
- 500. Roberto Efrain Diaz
- 501. Micquel Little, Associate University Librarian, University of California, San Francisco
- 502. Amanda Chalkley Library Technician, Australia
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- 504. Colleen Pawliuk
- 505. Rosalind McNally

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- 507. Gaynor Thomas (Health Librarian)
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- 509. Jonathan Jones, Subject Librarian, Cardiff University
- 510. Karen Pierce, Cataloguing Librarian (Medicine & Healthcare), Cardiff University, Wales, UK
- 511. Jennie Roe, Clinical Librarian, Swansea Bay University Health Board
- 512. Alison Westmaas (Cataloguing Librarian, Cardiff University)
- 513. Katie Wise, Royal Berkshire NHS Foundation Trust Library and Knowledge Services
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- 519. Tracey Stanley
- 520. Jessica McEwan, Librarian, University of Ottawa
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- 522. Igor Brbre, Information Scientist, Healthcare Improvement Scotland
- 523. Ariel Deardorff, University of California, San Francisco Library
- 524. Maha Kumaran
- 525. Raegan Villeneuve, MLIS student at University of Alberta
- 526. Cristina A. Pope, MS, MSM, Director, Health Sciences Library, SUNY Upstate Medical University
- 527. Jennifer Sullivan, MLIS, Academic & Research Librarian, Health Sciences Library, SUNY Upstate Medical University
- 528. Elizabeth Ten Have MLIS, Director of Operations, Scott Memorial Library, Thomas Jefferson University

- 529. Jane Orbell-Smith, JP (Qld) Qual, AFALIA, AALIA (DCP) Health, CHIA, Libraries' Manager, Industry Fellow USC & UQRedcliffe and Caboolture Hospital Libraries, Metro North Health, Queensland, Australia
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- 566. Vicky Fenerty University of Southampton Engagement Librarian
- 567. Kate Kelly, RCSI, Dublin
- 568. Ontario Public Health Libraries Association
- 569. Colleen MacKinnon

- 570. Colleen MacKinnon, User Experience Librarian
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- 573. Lukas Miller, Clinical Librarian, Saskatchewan Health Authority
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- 608. H Kiely, Evidence Reviewer, NHS, UK
- 609. Lori D Sloane, Data Manager, University of New Mexico Health Sciences Library and Informatics Center
- 610. Tiffany Garrett, Director of Library Services, Roseman University of Health Sciences
- 611. Shona Kirtley, Knowledge and Information Manager & Senior Research Information Specialist
- 612. Isabel Ramos-Wing, MSW, MLS

- 613. Fiona Watson, Library and Archives Manager, Royal College of Psychiatrists
- 614. Lorna Rutherford, Library and Information Service Manager, Royal College of Occupational Therapists
- 615. Helen Nield, Head of Library & Knowledge Services, British Dental Association Library
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- 635. rebecca jackson professor ucsf
- 636. Jessica Crosby, UCSF staff
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- 646. Z Mike Chirenje MD, Professor
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- 653. Jillian Hebert, UCSF

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- 718. Wanda Whitney, PhD, MLS, AHIP
- 719. Andrea Kepsel, Health Sciences Librarian, Michigan State University
- 720. Ginger Derrow
- 721. Brandon T. Pieczko, Ruth Lilly Medical Library, Indiana University School of Medicine
- 722. Orvie Dingwall, MLIS, University of Manitoba
- 723. Tyler Ostapyk
- 724. Christian West, Manager Library Services, University of Canberra, Australia
- 725. Charlie Macquarie, Digital Archivist, UCSF Archives & Special Collections
- 726. Lonnie A. Nelson, PhD, Associate Professor, College of Nursing, Washington State University, Assistant Director for Special Projects, Center for Native American Health Science