November 9, 2020

National Center for Health Statistics
ICD-10-CM Coordination and Maintenance Committee
3311 Toledo Road
Hyattsville, Maryland 20782

Submitted electronically to: nchsicd10CM@cdc.gov

RE: Comments on coding change requests presented at the ICD-10 Coordination & Maintenance Committee Meeting on September 9, 2020

Dear Ms. Bullock, and NCHS staff:

We write to support the ICD-10-CM coding change proposal for mild cognitive disorder due to known physiological conditions[i] from the American Psychiatric Association (APA) that was discussed at the September 9, 2020 ICD-10 Coordination & Maintenance Committee public meeting.[ii] This coding change would enable Alzheimer's disease pathology with mild cognitive impairment (MCI) to be coded separately from symptomatic dementia, in accordance with the Alzheimer's Disease Continuum.[iii] We also encourage the NCHS to include on the March 2021 ICD-10 Coordination and Maintenance Committee public meeting agenda (see page 3) a dementia severity coding proposal that was not able to be taken up during the September 9 meeting.

The APA's proposal would create new codes for MCI and mild neurocognitive disorder due to a known physiological condition, with the coder first coding the underlying physiological condition. We support this proposal because coding professionals would be allowed to report Alzheimer's disease pathology with MCI and without a requirement always to code dementia (which, by definition, is not present in the MCI stage of the Alzheimer's disease continuum). Also noted in the language of the proposal, underlying causes for MCI other than Alzheimer's disease -- such as Parkinson's disease and Huntington's disease -- also would be allowed to be coded. We consider these coding option additions, and the ability to code Alzheimer's disease pathology with MCI separate from dementia in the coding set, to be a vital change that will improve the ICD-10-CM coding set's accuracy and utility.

The APA's proposed coding changes delink the coding of Alzheimer's disease pathology with MCI from the automatic coding of dementia which additionally would support the proposal's creation of an "Excludes 1" note. (A type 1 Excludes note indicates that the codes excluded as part of the note never should be used in conjunction with the code preceding the note[iv]). Under the proposed Excludes 1 note, the codes for dementia are listed. Since Alzheimer's disease is one type of "underlying physiology" to code with MCI

due to known physiologic condition, and the dementia codes are in the Excludes 1 notes, then Alzheimer's disease pathology would be able to be coded without coding dementia. **We urge NCHS to finalize this proposal with this "Excludes 1" note containing the codes for dementia**, as this is a crucial change for the coding of Alzheimer's disease. This change would result in a clinician's diagnosis of Alzheimer's disease MCI to be coded distinctly from Alzheimer's disease dementia.

Additionally, **we recommend NCHS make the necessary updates to the Alzheimer's disease codes in G30, "Alzheimer's disease", so there is no conflict with the new updates in the F06.7 subset.** For example, in the G30 section, there are "code additional" notes present in order to add whether Alzheimer's disease dementia includes or excludes "behavioral disturbance" (as stated in the ICD-10-CM coding book[v]). If left unrevised, this would be confusing to clinicians and coders. We recommend revising the G30 section for dementia with or without behavioral disturbance to note "if applicable," similar to how delirium is referenced in ICD-10-CM.

The APA's proposed coding change would be consistent with and highly supportive of the three Healthy People 2030 (HP2030 cognitive impairment objectives[vi] along with improved utilization of the Annual Wellness Visit (AWV) cognitive assessment benefit.[vii] Simply put, accurately delinking MCI from Alzheimer's disease dementia will make it easier for patients (and their families) to report subjective cognitive concerns to their clinicians and for clinicians to raise the subject of cognitive health with patients (and their families) in the absence of symptoms indicative of progressed dementia. In turn, these earlier and more candid discussions with clinicians can lead to improved clinical outcomes and better shared decision making, which may include: reassuring a patient that reported symptoms are not indicative of cognitive impairment at all (i.e. consistent with normal cognitive aging); addressing any reversible causes of reported symptoms (e.g. treating vitamin deficiencies, sleep disorders, etc.); initiating or improving lifestyle modifications to reduce the risk that any MCI may progress to dementia (e.g. smoking cessation, hypertension mitigation, etc.); and advanced care planning in the event that MCI does eventually progress to dementia.

These earlier and more candid clinician-patient discussions, which the APA's proposed coding change would facilitate, are vitally important as recognized by the CDC: "The earlier dementia is diagnosed, the sooner care can be provided. A formal diagnosis allows people living with dementia to have access to available symptomatic treatments and interventions, build a care team, participate in support services, and potentially enroll in clinical trials. They and their caregivers can set systems in place to better manage medications, receive counseling, and address the challenges of other chronic conditions. Additional advantages include planning for future financial and legal needs and end of life choices."[viii] This is also consistent with the CDC's Healthy Brain Initiative Roadmap strategic objectives to improve professional care for people living with dementia.[ix]

As NCHS may be aware, far too few clinicians initiate timely discussions with their patients about cognitive health and cognitive impairment for a variety of reasons including time pressure, inadequate training about recognizing signs of impairment, varying degrees of discomfort around the sensitive topic of dementia, and an over-reliance (read: wishful thinking) that the patient or family member will raise the subject. Patients and their families often lack basic understanding of dementia, labor under stigma and myths such as that these diseases are a "normal part of aging," or expect

(for cultural or other reasons) that the health professional should and affirmatively would inquire about possible cognitive impairment. People with undetected MCI also are less likely to be accompanied by a caregiver informant at a medical appointment. In the aggregate, these and other factors result in cognitive impairment detection and diagnosis rates that are unacceptably low among the population at large and particularly among communities with disproportionate prevalence of Alzheimer's disease and other forms of dementia including women,[x] people with Down Syndrome and other intellectual disabilities,[xi] veterans,[xii] rural[xiii] and ethnic minorities.[xiv] Compounding this disease prevalence health disparity is the added burden that detection and diagnosis often come later in disease progression among these populations with profound negative consequences. As noted by a recent Alzheimer's Association report, "African-Americans tend to be diagnosed at a later stage of Alzheimer's disease — limiting the effectiveness of treatments that depend upon early intervention."[xv] Diagnoses are delayed because predicate detection is delayed: "African American and Latino patients are often diagnosed at later stages of the disease, with many of them experiencing a delay of up to seven years before their symptoms are evaluated...Delayed diagnosis may result in the patient having reached a greater severity of dementia by the time a diagnosis is made."[xvi] AWVs may provide the best opportunity to detect cognitive impairment in its earliest stages when lifestyle interventions and increased attention to managing comorbidities can have the largest impact in driving more positive health outcomes. The later cognitive impairment is detected, the later affected individuals and their families are able to begin grappling with – and deriving benefits from making -- the full gamut of consequential decisions including participation in clinical trials, use of FDA-approved symptomatic relief therapeutics, caregiver education, and planning involving legal, financial, spiritual and quality-of-life issues.

The APA's proposed coding change also would support Health Resources Services Administration (HRSA) curriculum that educates clinicians on properly making and conveying diagnosis.[xvii] and a free online toolkit from The Gerontological Society of America to help primary care teams detect and diagnose cognitive impairment.[xviii]

By fostering these earlier and more candid clinician-patient conversations about cognitive health, the APA's proposed coding change would be consistent with and highly supportive of work by the National Institutes of Health and its non-governmental partners to implement the *National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research*.[xix] The National Strategy works to engage broad segments of the public in the research enterprise, with a particular focus on underrepresented communities. As discussed previously, the later cognitive concerns are discussed and any impairment is detected and diagnosed, the less opportunity individuals have to participate in clinical research trials.

Additional Recommendation for the March 2021 ICD-10 Meeting Agenda

We are aware that the NCHS has received other coding change proposals for Alzheimer's disease including proposals that would address severity level (mild, moderate, or severe dementia), neuropsychiatric symptoms, and other issues. While we understand that these proposals could not be addressed during the September 9 meeting, **we encourage the NCHS to discuss all these important issues at the March 2021 ICD-10 Coordination and Maintenance Committee meeting**, as there are

new therapeutics that may gain FDA approval in early 2021. These therapeutics could improve the quality of life and clinical outcomes for millions of Americans with MCI or with different severity of dementia symptomatology. Therefore, it is vital to ensure the ICD-10-CM coding set is up to date with current clinical practice, since diagnosis codes are essential to facilitating individualized clinical care.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and other forms of dementia. For any questions or additional information about this or other policy issues, please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),[xx] ikremer@leadcoalition.org or (571) 383-9916.

Sincerely,

Abe's Garden Alzheimer's Center of Excellence

Acadia Pharmaceuticals Inc

Accelerate Cure/Treatments for Alzheimer's Disease (ACT-AD)

ActivistsAgainstAlzheimer's Network

ADvancing States

African American Network Against Alzheimer's

AgeneBio

Neelum T. Aggarwal, MD (Rush University Medical Center*)

Aging Life Care Association®

Paul S. Aisen, MD (Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute*)

Alliance for Aging Research

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer's Drug Discovery Foundation

Alzheimer's Foundation of America

Alzheimer's Los Angeles

Alzheimer's Mississippi

Alzheimer's New Jersey

Alzheimer's Orange County

Alzheimer's San Diego

Alzheimer's Tennessee

Alzheimer's Texas

American Academy of Neurology

American Association for Geriatric Psychiatry

American Brain Coalition

American Geriatrics Society

American Neurological Association

American Society of Consultant Pharmacists (ASCP)

Brian S. Appleby, M.D. (Case Western Reserve University School of Medicine*)

Argentum | Expanding Senior Living

Laura D. Baker, PhD (Wake Forest University Health Sciences*)

Banner Alzheimer's Institute

Banner Health

David M. Bass, PhD (Benjamin Rose Institute on Aging*)

Baylor Scott & White Health

Beating Alzheimer's by Embracing Science

Benjamin Rose Institute on Aging

Biogen

Deborah Blacker, MD, ScD (Harvard Medical School and Harvard School of Public Health*)

B'nai B'rith International

Soo Borson MD (Minnesota Brain Aging Research Collaborative*)

The Brain Donor Project

James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*)

Bridge Builder Strategies

BrightFocus Foundation

Christopher M. Callahan, MD (Indiana University Center for Aging Research*)

Caregiver Action Network

Caregiver Voices United

CaringKind, The Heart of Alzheimer's Caregiving

Centene

Center for Alzheimer Research and Treatment, Harvard Medical School

Center for BrainHealth at The University of Texas at Dallas

Center for Memory Health at Hebrew SeniorLife

Center to Advance Palliative Care

Chambers-Grundy Center for Transformative Neuroscience, Department of Brain Health, UNLV

Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)

Joshua Chodosh, MD, MSHS, FACP (New York University*)

ClergyAgainstAlzheimer's Network

Cleveland Clinic Foundation

Coalition of Wisconsin Aging and Health Groups

Cognitive Dynamics Foundation

Suzanne Craft, PhD (Wake Forest School of Medicine*)

Critical Path for Alzheimer's Disease (CPAD) Consortium, Critical Path Institute (C-Path)

Jeffrey Cummings, MD, ScD (University of Nevada Las Vegas*)

Darrell K. Royal Fund for Alzheimer's Research

Walter Dawson, Dphil (Oregon Health & Science University*)

Dementia Alliance of North Carolina

Department of Neurology, Washington University School of Medicine

N. Maritza Dowling PhD (The George Washington University School of Nursing*)

Drexel University College of Nursing and Health Professions

Duke Dementia Family Support Program

Eisai Co., Ltd.

Eli Lilly and Company

The Emory Goizueta Alzheimer's Disease Research Center

Gary Epstein-Lubow, MD (Alpert Medical School of Brown University*)

Faith United Against Alzheimer's Coalition

Family Caregiver Alliance

Brent P. Forester, MD, MSc (Harvard Medical School*)

Fujirebio

Seth A. Gale, M.D. (Harvard Medical School*)

Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai*)

Joseph E. Gaugler, PhD (School of Public Health, University of Minnesota*)

Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine*)

Georgetown University Medical Center Memory Disorders Program

Gerontological Advanced Practice Nurses Association

Gerontological Society of America

Laura Gillen, MS (McDaniel College*)

Laura N. Gitlin, PhD (Drexel University, College of Nursing and Health Professions*)

Global Alzheimer's Platform Foundation

Global Coalition on Aging

Danielle Goldfarb, MD (University of Arizona College of Medicine*)

Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center*)

Hadassah, The Women's Zionist Organization of America, Inc.

HFC (formerly Hilarity for Charity)

Nancy A. Hodgson, RN, PhD, FAAN (University of Pennsylvania School of Nursing*)

David P Hoffman DPS CCE (Maria College*)

David M. Holtzman, MD (Washington University School of Medicine, Department of Neurology*)

Home Instead Senior Care

Huffington Center on Aging, Baylor College of Medicine

Huntington's Disease Society of America

International Association for Indigenous Aging

Iona Senior Services

IQVIA

Janssen R&D

Kathy Jedrziewski, PhD (University of Pennsylvania*)

Johns Hopkins Memory and Alzheimer's Treatment Center

Katherine S. Judge, PhD (Cleveland State University*)

Jason Karlawish, MD (Perelman School of Medicine, University of Pennsylvania*)

Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute

Walter A. Kukull, PhD (School of Public Health, University of Washington*)

Latino Alzheimer's and Memory Disorders Alliance

LatinosAgainstAlzheimer's

LeadingAge

Allan Levey, MD, PhD (Emory University School of Medicine*)

Lewy Body Dementia Association

Life Molecular Imaging

Linked Senior, Inc

Livpact Inc.

Lou Ruvo Center for Brain Health

Lundbeck

Kostas Lyketsos, M.D., M.H.S. (Johns Hopkins Memory and Alzheimer's Treatment Center*)

Yannick Marchalant, Ph.D. (Central Michigan University*)

David X. Marquez, PhD (Department of Kinesiology and Nutrition, University of Illinois at Chicago*)

Merck

Marsel Mesulam, MD (Northwestern University Feinberg School of Medicine*)

Metropolitan Area Agency on Aging/ACT on Alzheimer's

Michela Gallagher, PhD (Johns Hopkins University School of Medicine*)

Michigan State University Alzheimer's Alliance

Milken Institute Center for the Future of Aging

Minnesota Association of Area Agencies on Aging

Minnesota Brain Aging Research Collaborative

David G. Morgan, PhD (Michigan State University*)

Darby Morhardt, PhD, LCSW (Northwestern University Feinberg School of Medicine*)

Mount Sinai Center for Cognitive Health

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association of Activity Professionals

National Association of Area Agencies on Aging (n4a)

National Association of Chronic Disease Directors

National Association of State Long-Term Care Ombudsman Programs (NASOP)

National Caucus and Center on Black Aged, Inc. (NCBA)

National Certification Council for Activity Professionals

National Consumer Voice for Quality Long-Term Care

National Council for Behavioral Health

National Down Syndrome Society

National Hospice and Palliative Care Organization (NHPCO)

National Task Group on Intellectual Disabilities and Dementia Practices

NFL Neurological Center

Noah Homes

NYU Langone Alzheimer's Disease Center

NYU Langone Center on Cognitive Neurology

NYU Langone Health

The Ohio Council for Cognitive Health

Otsuka America Pharmaceutical Inc.

Van Ta Park, PhD, MPH (University of California, San Francisco*)

Monica W. Parker, MD (Goizueta Alzheimer's Disease Research Center, Emory University*)

Pat Summitt Foundation

Pioneer Network

Planetree International, Inc.

Anton P. Porsteinsson, M.D. (University of Rochester School of Medicine and Dentistry*)

Daniel C. Potts, MD, FAAN (University of Alabama College of Community Health Sciences*)

Daniel Z. Press, MD (Harvard Medical School*)

Prevent Alzheimer's Disease 2020

Eric Reiman, MD (Banner Alzheimer's Institute*)

ResearchersAgainstAlzheimer's

David B. Reuben, MD (David Geffen School of Medicine at UCLA*)

Theresa Rohr-Kirchgraber, MD, FACP, FAMWA (Indiana University National Center of Excellence of Women's Health*)

Marwan Sabbagh, MD, FAAN (Lou Ruvo Center for Brain Health*)

Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)

Quincy Miles Samus, PhD, MS (Johns Hopkins School of Medicine*)

Sanford Health

Savonix, Inc.

Second Wind Dreams, Inc./ Virtual Dementia Tour

Amanda G. Smith, M.D. (USF Health Byrd Alzheimer's Institute*)

SNP Alliance

Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School*)

Alan B. Stevens, PhD (Baylor Scott & White Health, Center for Healthcare Policy*)

Beth Stevens, PhD (Harvard Medical School*)

Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)

Pierre N. Tariot, MD (University of Arizona College of Medicine*)

The Evangelical Lutheran Good Samaritan Society

Geoffrey Tremont, Ph.D., ABPP-CN (Alpert Medical School of Brown University*)

John Q. Trojanowski M.D., Ph.D. (Perelman School of Medicine at the University of Pennsylvania*)

R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*)

University of Pennsylvania Alzheimer's Disease Core Center

University of Pennsylvania Center for Neurodegenerative Disease Research

University of Pennsylvania Center on Alpha-synuclein Strains in Alzheimer Disease & Related Dementias

University of Rochester Alzheimer's Disease Care, Research and Education Program (AD-CARE)

UsAgainstAlzheimer's, LEAD Coalition co-convener

USF Health Byrd Alzheimer's Institute

VeteransAgainstAlzheimer's

Anand Viswanathan, MD, PhD (Massachusetts General Hospital and Alzheimer's Disease Research Center*)

Stella L. Volpe, PhD, RDN, ACSM-CEP, FACSM (Virginia Tech*)

Volunteers of America, LEAD Coalition co-convener

Victoria Walker, MD CMD (Sanford School of Medicine, University of South Dakota*)

David A. Weidman, MD, FAAN (Banner Alzheimer's Institute*)

Carol J. Whitlatch, PhD (Benjamin Rose Institute on Aging*)

Nancy Wilson, MA LCSW (Baylor College of Medicine*)

Jennifer Wolff, PhD (Johns Hopkins Bloomberg School of Public Health*)

WomenAgainstAlzheimer's

Women's Brain Project

The Youth Movement Against Alzheimer's

Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of affiliated institutions.

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[i] Centers for Disease Control and Prevention (CDC), *ICD-10 Coordination and Maintenance Committee Meeting — September 8-9, 2020*, Atlanta (GA): CDC, 2020, pages 61-64. Online: https://www.cdc.gov/nchs/data/icd/Topic-packet-September-8-9.2020.pdf.

[ii] National Center on Health Statistics, "ICD-10 Coordination and Maintenance Committee," Centers for Disease Control and Prevention, February 27, 2020. Online: https://www.cdc.gov/nchs/icd/icd10_maintenance.htm

[iii] Alzheimer's Association. 2020 Alzheimer's Disease Facts and Figures. Alzheimer's Dementia 2020a;16(3):391+.

[iv] Centers for Medicare and Medicaid Services (CMS), *ICD-10-CM Official Guidelines for Coding and Reporting, FY 2019*, Baltimore (MD): CMS, 2019, page 11 (12. Excludes Notes, a. Excludes 1). Online at: https://www.cms.gov/Medicare/Coding/ICD10/Downloads/2019-ICD10-Coding-Guidelines-.pdf.

[v] Centers for Disease Control and Prevention, National Center for Health Statistics (NCHS), *International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM)*, Atlanta (GA): NCHS, July 17, 2020, page 306 (G30). Online at: https://www.cdc.gov/nchs/icd/icd10cm.htm. (Note that the link will download the tabular PDF for FY 2021 release.)

[vi] https://health.gov/healthypeople/objectives-and-data/browse-objectives/dementias

[vii] https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AWV_Chart_ICN905706.pdf

[viii] https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf

[ix] https://www.cdc.gov/aging/healthybrain/roadmap.htm

[x] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6226313/

[xi] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4184282/

[xii] https://www.aginglifecarejournal.org/dementia-risk-factors-in-veterans/

[xiii] https://www.rand.org/pubs/external_publications/EP67436.html

[xiv] https://www.sciencedirect.com/science/article/pii/S1552526018332527?via%3Dihub

[xv] https://www.alz.org/media/Documents/african-americans-silent-epidemic-r.pdf

[xvi] https://www.questia.com/read/1P3-1862957491/disparities-in-the-diagnosis-and-treatment-of-alzheimer-s

[xvii] https://bhw.hrsa.gov/sites/default/files/bhw/grants/geriatrics/module-2-diagnosing-dementia.pptx

[xviii] http://www.geron.org/kaer

[xix] https://www.nia.nih.gov/sites/default/files/2018-10/alzheimers-disease-recruitment-strategy-final.pdf

[xx] http://www.leadcoalition.org Leaders Engaged on Alzheimer's Disease (the LEAD Coalition) is a diverse national coalition of member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and home and residential care providers, large health systems, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on dementia in all its causes -- including Alzheimer's disease, vascular disease, Lewy body dementia, and frontotemporal degeneration -- and to accelerate transformational progress in detection and diagnosis, care and support, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.