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December 14, 2018

NIH Nutrition Research Task Force
National Institutes for Health
Christopher J. Lynch, Ph.D.
Executive Secretary, NIH Nutrition Research Task Force
Director, NIDDK's Office of Nutrition Research
900 Rockville Pike
Bethesda, MD 20892

**Submitted Electronically to nutritionresearch@niddk.nih.gov
Attention: Public Comments to the Draft First Strategic Plan for NIH Nutrition Research- Academy for Eating Disorders and Eating Disorders Coalition**

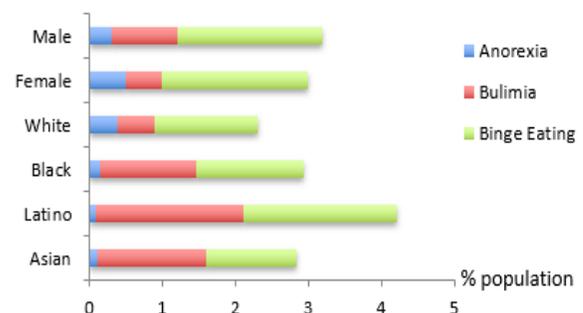
Dear Dr. Lynch,

The Academy for Eating Disorders (AED) and Eating Disorders Coalition (EDC) read with great interest your Draft Strategic Plan for the National Institutes of Health (NIH) Nutrition Research and applaud your cross-cutting and innovative thinking in developing the plan. Given the strong connection between nutrition and the complex, serious mental illness of eating disorders, we are writing to appeal to you to include eating disorder research specifically in your plan.

Overall, we offer the perspective of the eating disorders community at-large and hope you will take into consideration our comments. The AED is a global, multidisciplinary professional association leading the field in eating disorders research, education, treatment, and prevention. The EDC is a nonprofit organization representing a coalition of individuals nationwide in the eating disorders community, including patient advocates, academics, treatment providers, and advocacy organizations across the nation.

The AED research professionals are engaged in important and life-saving work related to every area of your Nutrition Research priorities. Eating disorders are serious mental illnesses and among **the most fatal** psychiatric disorders in the United States: specifically, individuals with anorexia nervosa have an estimated six times greater mortality risk than the general population.¹ For bulimia nervosa and binge-eating disorder, mortality risk is double that of the general population.¹ While **30 million Americans will experience an eating**

Lifetime prevalence of eating disorders in the US



¹ Chesney, E., Goodwin, G. M., & Fazel, S. (2014). Risks of all-cause and suicide mortality in mental disorders: a meta-review. *World Psychiatry, 13*(2):153-60.

disorder in their lifetime,^{2,3} only 1 in 3 will receive care – and an alarming number will die because they did not receive a timely diagnosis and appropriate care. Additionally, the negative physical and psychosocial impacts of eating disorders and disordered eating behaviors, cut across age, gender, race/ethnicity, and socioeconomic subgroups.

Eating disorders, including the specific disorders of anorexia nervosa, bulimia nervosa, binge-eating disorder, avoidant/restrictive food intake disorder, and other specified feeding and eating disorders, are complex, biologically-based illnesses with a strong genetic component and psychosocial influences.⁴ The following describes clinical categorizations of the most prevalent eating disorders under the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-5) or the International Statistical Classification of Diseases and Related Health Programs (ICD-10):

- **Anorexia Nervosa (AN):** Restriction of energy intake relative to an individual’s requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory and health status. Disturbance of body image, an intense fear of gaining weight, lack of recognition of the seriousness of the illness and/or behaviors that interfere with weight gain are also present.
- **Bulimia Nervosa (BN):** Binge eating (eating a large amount of food in a relatively short period of time with a concomitant sense of loss of control) with compensatory behavior once a week or more for at least three months. Disturbance of body image, an intense fear of gaining weight and lack of recognition of the seriousness of the illness may also be present.
- **Binge-Eating Disorder (BED):** Binge eating, in the absence of compensatory behavior, once a week for at least three months. Binge eating episodes are associated with eating: rapidly, when not hungry, until extreme fullness, and/or associated with depression, shame or guilt.
- **Avoidant/Restrictive Food Intake Disorder (ARFID):** Significant weight loss, nutritional deficiency, dependence on nutritional supplement or marked interference with psychosocial functioning due to caloric and/or nutrient restriction, but without weight or shape concerns.
- **Other Specified Feeding or Eating Disorders (OSFED):** An eating disorder that does not meet full criteria for one of the above categories but has specific disordered eating behaviors such as restricting intake, purging and/or binge eating as key features.

Of particular concern is the significant medical and psychiatric comorbidity associated with eating disorders, as they are associated with a range of medical morbidity including cardiovascular, gastrointestinal, musculoskeletal, dermatologic, endocrine, hematological, reproductive, and neurological systems.^{5,6} In addition, eating disorders and disordered eating are specifically comorbid with disease states prioritized by the NIDDK. For example, eating disorders and disordered eating behaviors are found to be more common in individuals with Type 1 diabetes mellitus.^{7,8} Due to the complications associated with hypo- or hyperglycemia, studying how behaviors impact glucose control is vital to health in this population. Furthermore, individuals with bulimia nervosa or binge-eating disorder have an increased risk of Type 2 diabetes.⁹ In fact, binge-eating disorder (the most prevalent of all eating disorders)³ has demonstrated significant comorbidity with diabetes, metabolic syndrome, and gastrointestinal disease above and beyond the risk conferred by

² Hudson, J. I., Hiripi, E., Pope, H. G., & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the national comorbidity survey replication. *Biol Psych*, 61(3):348–58.

³Le Grange, D., Swanson, S. A., Crow, S. J., & Merikangas, K. R. (2012). Eating disorder not otherwise specified presentation in the US population. *Int J Eat Disord*, 45(5):711-18.

⁴ American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, D.C: American Psychiatric Association.

⁵ Westmoreland, P., Krantz, M. J., & Mehler, P. S. (2016). Medical complications of anorexia nervosa and bulimia. *Am J Med*, 129(1):30–7.

⁶ Thornton, L. M., Watson, H. J., Jangmo, A., Welch, E., Wiklund, C., von Hausswolff-Juhlin, Y., . . . Bulik, C. M. (2017). Binge-eating disorder in the Swedish national registers: somatic comorbidity. *Int J Eat Disord*, 50(1):58-65.

⁷ Young, V., Eiser, C., Johnson, B., Brierley, S., Epton, T., Elliott, J., & Heller, S. (2013). Eating problems in adolescents with Type 1 diabetes: a systematic review with meta-analysis. *Diabetic Med*, 30(2):189-98.

⁸ Hanlan, M. E., Griffith, J., Patel, N., & Jaser, S. S. (2013). Eating disorders and disordered eating in type 1 diabetes: prevalence, screening, and treatment options. *Curr Diab Rep*, 13(6):909-16.

⁹ Raevuori, A., Suokas, J., Haukka, J., Gissler, M., Linna, M., Grainger, M., & Suvisaari, J. (2015). Highly increased risk of type 2 diabetes in patients with binge eating disorder and bulimia nervosa. *Int J Eat Disord*, 48(6):555-62.

obesity,³ a commonly comorbid condition among those with binge-eating disorder.¹⁰ Evidence suggests that individuals with Type 2 diabetes who experience binge eating may need treatment above and beyond traditional best practices (e.g. intensive lifestyle intervention).¹¹

In addition to the significant psychiatric and medical comorbidity, disordered eating behaviors (e.g., dieting, unhealthy and extreme weight control behaviors, binge eating), are also a great public health concern due to their elevated prevalence estimates and harmful consequences. It is estimated that **between 50-60% of adolescents and young adults engage in disordered eating behaviors**;¹² further, engagement in these behaviors places individuals at risk for significant negative physical and psychosocial outcomes, including unhealthy weight gain, obesity, clinical eating disorders, as well as lower levels of body image, self-esteem and increased depressive symptoms.^{13,14,15}

Given the number of Americans impacted by eating disorders and disordered eating, and the associated morbidity and mortality of these conditions, research on the identification, prevention, and treatment of eating disorders and disordered eating must be a public health priority. Our members are deeply engaged in the types of research that you seek to prioritize in your draft Strategic Plan for NIH Nutrition Research including: leading-edge primary, secondary, and tertiary prevention programs aimed at decreasing the number of individuals impacted by eating disorders and disordered eating; studies examining the impact of the illness on an affected individual's microbiome, nutrient absorption, and metabolism; and the establishment of effective refeeding protocols to improve recovery time from eating disorders and limit hospital stay.^{16,17,18,19} Patients being treated by the physicians, psychologists, and dietitians in AED membership present some of the richest cases for studying outlying responses to dietary interventions.^{20,21,22,23}

Furthermore, research in eating disorders has profound value across the spectrum of the nutritional field; eating disorder research creates knowledge that cuts across medical diagnoses, providing valuable insight into how to maximize the nutritional status of individuals impacted by a variety of disease states (e.g. cancer, chronic gastrointestinal diseases) and

¹⁰ Kessler, R.C., Berglund, P.A., Chiu, W.T., Dietz, A.C., Hudson, J.I., Shahly, V., ... Xavier, M. The prevalence and correlates of binge eating disorder in the World Health Organization World Mental Health Surveys. *Biol Psych*, 73(9):904-14.

¹¹ Chao, A. M., Wadden, T. A., Gorin, A. A., Shaw Tronieri, J., Pearl, R. L., Bakizada, Z. M., ... & Berkowitz, R. I. (2017). Binge Eating and Weight Loss Outcomes in Individuals with Type 2 Diabetes: 4-Year Results from the Look AHEAD Study. *Obesity*, 25(11):1830-7.

¹² Neumark-Sztainer, D., Wall, M., Larson, N. I., Eisenberg, M. E., & Loth, K. (2011). Dieting and disordered eating behaviors from adolescence to young adulthood: findings from a 10-year longitudinal study. *J Am Diet Assoc*, 111(7):1004-11.

¹³ Tanofsky-Kraff, M., Yanovski, S. Z., Schvey, N. A., Olsen, C. H., Gustafson, J., & Yanovski, J. A. (2009). A prospective study of loss of control eating for body weight gain in children at high risk for adult obesity. *Int J Eat Disord*, 42(1):26-30.

¹⁴ Neumark-Sztainer, D., Wall, M., Story, M., & Standish, A. R. (2012). Dieting and unhealthy weight control behaviors during adolescence: associations with 10-year changes in body mass index. *J Adolesc Health*, 50(1):80-6.

¹⁵ Goldschmidt, A. B., Wall, M. M., Choo, T. H. J., Evans, E. W., Jelalian, E., Larson, N., & Neumark-Sztainer, D. (2018). Fifteen-year weight and disordered eating patterns among community-based adolescents. *Am J Prev Med*, 54(1):e21-9.

¹⁶ Nieuwdorp, M., Gilijamse, P.W., Pai, N., Kaplan, L.M. (2014). Role of the microbiome in energy regulation and metabolism. *J Gastro*, 146 (6):1525-33.

¹⁷ Liou, A.P., Paziuk, M., Luevano, J.M., Machineni, S., Turnbaugh, P.J., & Kaplan, L.M. (2013). Conserved shifts in the gut microbiota due to gastric bypass reduce host weight and adiposity. *Sc. Tranl. Med*, 5(178):178ra41.

¹⁸ Kleiman, S.C., Watson, H.J., Bulik-Sullivan, E.C., Huh, E.Y., Tarantino, L.M., Bulik, C.M., Carroll, I.M. (2015). The intestinal microbiota in acute anorexia nervosa and during renourishment: Relationship to depression, anxiety, and eating disorder psychopathology. *Psychosom Med*, 77(9): 969-81.

¹⁹ Mack, I., Cuntz, U., Grämer, C., Niedermaier, S. Pohl, C., Schwiertz, A., ... Penders, J. (2016). Weight gain in anorexia nervosa does not ameliorate the fecal microbiota, branched chain fatty acid profiles, and gastrointestinal complaints. *Sci Rep*, 6:26572.

²⁰ Calugi, S., Ruocco, A., El Ghoch, M., Andrea, C., Geccherle, E., Sartori, F., & Dalle Grave, R. (2016). Residential cognitive-behavioral weight-loss intervention for obesity with and without binge-eating disorder: A prospective case-control study with five-year follow-up. *Int. J Eat Disord*, 49(7):723-30.

²¹ Hartmann, A.S., Winfried, J.C., & Hilbert, R.A. (2012). Psychosocial risk factors of loss of control eating in primary school children: A retrospective case-control study. *Int J Eat Disord*, 45(6):751-8.

²² Vierbergh, L.V., Braet, C., & Goossens, L. (2008). Dysfunctional schemas and eating pathology in overweight youth: A case-control study. *Int. J Eat Disord*, 42(5):437-42.

²³ Davis, C., Levitan R.D., Carter, J., Kaplan A.S., Reid, C., Curtis, C., ... & Kennedy J.L. (2007). Personality and eating behaviors: A case-control study of binge eating disorder. *Int J Eat Disord*, 41(3):243-50.

deepening our understanding of how to implement successful prevention programs targeting other priority public health crises (e.g. depression, substance use).^{24,25,26,27,28}

Research in eating disorders may also inform how dietitians can maximize positive health outcomes for patients. For example, although most community practices involve a dietitian as a part of eating disorder treatment teams, formal research regarding the role of the dietitian on these teams is largely absent. Thus, dissemination and implementation research may help determine if the inclusion of an experienced dietitian on treatment teams improves treatment or even if a non-physician clinician, such as a dietitian or nurse practitioner, might be able to successfully deliver a manualized treatment (e.g., family-based treatment, cognitive-behavioral therapy), in lieu of a physician or allied health professional.^{29,30,31,32,33} Expanding the healthcare workforce trained in eating disorders is particularly crucial as limited numbers of healthcare professionals specialize in this area.³⁴

In light of the above, below you will find several specific research priority suggestions that would impact individuals with eating disorders and disordered eating according to each theme identified in the Draft Strategic Plan for NIH Nutrition Research. These ideas are not intended to be exhaustive, but rather to highlight how a commitment to eating disorders research aligns seamlessly with the Strategic Plan for Nutrition Research put forth by the NIH.

1. Investigate Nutritional Biochemistry, Physiology, and the Microbiome

- Explore the relationship between the microbiome and metabolism, including the hypometabolic state in dietary restriction and the hypermetabolic state in refeeding after starvation.
- Elucidate how the gut microbiome and the gut-brain axis interplay affects mood and psychological symptoms in patients with eating disorders.

2. Assess the Role of Nutrition and Dietary Patterns in Development, Health, and Disease Across Life Stages

- Determine the impact of early feeding behaviors on the development of avoidant/restrictive food intake disorder and failure to thrive.
- Examine any unintentional and adverse effects of nutrition recommendations for children and adolescents with respect to the development of restrictive eating behaviors and risk for eating disorders.
- Examine current nutrition education activities in primary and secondary schools and their effect on children's attitudes and behaviors regarding food, eating, and body image.
- Examine how and when disordered eating behaviors and eating disorders emerge and how timing predicts subsequent physical and psychosocial disease risk.

3. Explore Individual Variability in Response to Diet Interventions to Inform Nutrition Science, Improve

²⁴ Langer, C.J., Hoffman, J.P., Ottery, F.D. (2001). Clinical significance of weight loss in cancer patients: rationale for the use of anabolic agents in the treatment of cancer-related cachexia. *Nutrition*, 17(1 Suppl):S1-20.

²⁵ Van Cutsem, E. & Arends, J. (2005). The causes and consequences of cancer-associated malnutrition. *Eur J Oncol Nurs*, 9(Suppl 2):S51-63.

²⁶ Santarpia, L., Contaldo, F., & Pasanisi, F. (2011). Nutritional screening and early treatment of malnutrition in cancer patients. *J Cachexia Sarcopenia Muscle*, 2(1):27-35.

²⁷ Murtaugh, M.A. & Frech, T.M. (2013). Nutritional status and gastrointestinal symptoms in systemic sclerosis patients. *Clin Nutr*, 32(1):130-5.

²⁸ Manning, L.P., & Biesiekierski, J.R. (2018). Use of dietary interventions for functional gastrointestinal disorders. *Curr Opin Pharmacol*, 43:132-8.

²⁹ American Dietetic Association. (2006). Position of the American Dietetic Association: Nutrition Intervention in the treatment of anorexia nervosa, bulimia nervosa, and other eating disorders. *J Am Diet Assoc*, 106(12):2073-82.

³⁰ Whisenant, S.L., & Smith, B.A. (1995). Eating disorders: current nutrition therapy and perceived needs dietetics education and research. *J Am Diet Assoc*, 95(10):1109-12.

³¹ Ozier, A.D. & Henry, B.W. (2011). Position of the American Dietetic Association: nutrition intervention in the treatment of eating disorders, *J Am Diet Assoc*, 111(8):1236-41.

³² Reiter, C.S. & Graves, L. (2010). Nutrition therapy for eating disorders. *Nutr Clin Pract*, 25(2):122-36.

³³ Peebles, R., Lesser, A., Park, C. C., Heckert, K., Timko, C. A., Lantzouni, E., ... & Weaver, L. (2017). Outcomes of an inpatient medical nutritional rehabilitation protocol in children and adolescents with eating disorders. *J Eat Disord*, 5:7.

³⁴ Ali, K., Farrer, L., Fassnacht, D.B., Gulliver, A., Bauer, S., & Griffiths, K.M. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review. *Int J Eat Disord*, 50(1):9-21.

Health, and Prevent Disease

- Evaluate the impact of existing and emergent obesity prevention interventions on eating disorders and disordered eating behaviors.
- Explore the effects of clinically prescribed weight loss through caloric restriction on mental health and the development of obsessive-compulsive behaviors such as body dissatisfaction and food rumination.
- Investigate alternative weight control methods that may be more sustainable for individuals who do not respond to traditional behavioral weight loss programming; use SMART study designs to identify what approaches work best for sub-types of individuals followed by precision medicine approaches to best match individuals to treatment plans most likely to be successful.

4. Enhance Clinical Nutrition Research to Improve Health Outcomes in Patients

- Identify and evaluate screening tools in clinical settings for assessing malnutrition from anorexia nervosa, bulimia nervosa, and other eating disorders.
- Develop and test clinical protocols to assess recovery from malnutrition and starvation, brought on by eating disorders or other disease states (e.g. cancer).
- Identify or establish validated instruments to systematically screen for eating disorders and disordered eating within primary care settings; consistent screening will provide much needed surveillance data illuminating the scope of the problem and identifying opportunities for primary, secondary and tertiary prevention efforts.
- Identify best practices in clinical settings that make use of multidisciplinary teams and facilitate optimal use of physicians and allied health professionals.

5. Advance Implementation Science to Increase the Use of Effective Nutritional Interventions

- Identify current nutrition interventions that may inadvertently contribute to weight stigma, weight bias, and eating disorders; develop a plan for evidence-based de-implementation of identified practices that exist within primary and specialty care settings.
- Identify opportunities to introduce evidence-based primary, secondary, and tertiary eating disorder and disordered eating prevention efforts into the appropriate setting for implementation and dissemination.
- Implement treatment best practices in primary and specialty clinical settings that utilize multidisciplinary teams to facilitate optimal use of physicians and allied health professionals.

6. Develop and Refine Research Methods and Tools

- Develop and validate an instrument or combination of existing instruments to systematically assess and monitor the prevalence of eating disorders and disordered eating behaviors on a national level, through existing surveillance systems (e.g. NHANES) and within primary care settings.

7. Support Training to Build an Outstanding Nutrition Research Workforce

- Develop education and training programs that allow trainees to simultaneously work toward becoming a Registered Dietitian while developing the skills needed to conduct, evaluate, disseminate and implement nutrition research effectively.
- Encourage interdisciplinary collaboration and training with primary care providers, psychologists and other mental health professionals to be able to better assess and identify individuals who may be struggling with an eating disorder or engaging in disordered eating behaviors and to direct those individuals to a place where they will be helped.

Given the above, research focused on eating disorders and disordered eating behaviors aligns seamlessly with the priority research themes outlined in the NIH Draft Strategic Plan for Nutrition Research and will expand your current goals for the next ten years. Broadening your focus to include research on eating disorders will amplify the ability of the NIH to move science forward through research in a way that will have a profound impact on the physical and psychosocial health of individuals throughout the United States. In conclusion, we urge you to specifically address the relationship between nutritional health and eating disorders in your strategic plan. We would be most happy to meet with you to explore specific concepts that you might include.

With gratitude for the important work that you do,



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AED Advocacy and Communications Committee
AED Nutrition Special Interest Group
AED Epidemiology and Public Health Practice Special Interest Group

