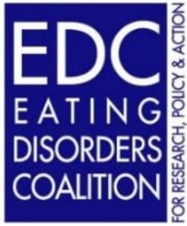

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December 19, 2017

Centers for Disease Control and Prevention
Attention: CDC Desk Officer
Office of Management and Budget
725 17th Street, NW
Washington, DC 20503

RE: Eating Disorders Coalition—Centers for Disease Control and Prevention [30Day-18-0214] OMB Control Number 0920-0214

Dear Director Dr. Brenda Fitzgerald:

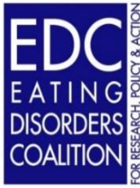
On behalf of the members of the Eating Disorders Coalition (EDC), we are writing to applaud the Centers for Disease Control and Prevention (CDC) on its continued work to implement the National Health Interview Survey (NHIS) as authorized under Section 306 of the Public Health Service Act (42 U.S.C.). Below you will find the EDC's recommendations on how to enhance the quality and utility of NHIS data collection in response to the original August 21, 2017 notice, and November 29, 2017 30-day extension notice.

The Eating Disorders Coalition is an alliance of eating disorders treatment providers, advocacy organizations, researchers, and families and individuals affected by eating disorders across the nation. Members include trade organizations, law firms specializing in mental health insurance compliance, and national patient advocacy organizations. Members include, but are not limited to, the Academy for Eating Disorders (national, based in VA), the National Eating Disorders Association (national, based in NY), Residential Eating Disorders Consortium (national), the Alliance for Eating Disorders Awareness (located in FL), Kantor & Kantor, LLP (located in CA), Wrobel & Smith, PLLP (located in MN), Gail R. Schoenbach FREED Foundation (located in NJ), Binge Eating Disorder Association (national, based in MD), The International Association of Eating Disorders Professionals Foundation (international), International Eating Disorder Action (international), Multi-Service Eating Disorders Association (located in MA), the Eating Disorders Coalition of Iowa (located in IA), Eating Disorders Foundation (located in CO), Eating Disorder FEAST (international, based in WI), International Federation of Eating Disorders Dietitians (international), The National Association of Anorexia and Associated Eating Disorders (national, based in IL), and Harvard University's public health incubator - Strategic Training Initiative for the Prevention of Eating Disorders (located in MA).

The Eating Disorders Coalition members and advocates are directly impacted by the data collected by NHIS due to the lack of data collected on the common and serious mental illness of eating disorders. This lack of data collection prevents government, academic and private researchers from advancing detection, tracking and prevention of eating disorders.

I. Background

NHIS has been a major source of national health data over the last 60 years and continues to ask questions on access and barriers to care, disability and functioning, and children's mental health, amongst other items. We commend you for your work



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in collecting this important health data in order to detect, track, assess and identify public health issues so that we can best coordinate prevention efforts for these at-risk populations. As mentioned in the original proposed data collection on August 21, 2017, these data have long been used by government, academic and private researchers to evaluate general health and specific issues, such as smoking, diabetes, health care coverage and access to care, as well as providing a leading source of data for the "Health US" program identified as a NHIS priority.

Currently the CDC national surveillance systems have limited supplementary surveys with questions on disordered eating behaviors, and no mandatory data collection on the signs and symptoms of eating disorders in children or adults. While we applaud the CDC for doing some data collection within NHANES on a few disordered eating behaviors within optional sub-surveys, we unfortunately are missing comprehensive data collection on eating disorders that we once had under the Youth Risk Behavioral Health Surveillance System (YRBSS).

II. Recommendation to Enhance the Quality and Utility of NHIS Collection Information to Include Items Assessing Signs and Symptoms of the Common and Serious Mental Illness of Eating Disorders in 2018 NHIS Questionnaire

As we applaud the CDC's continued data collection effort under NHIS, we encourage the CDC, as a way to enhance the quality and utility of this information, to include questions on the signs and symptoms of the serious and common mental illness of eating disorders. Including such questions would be in-line with the statutory authority of Section 306 of the Public Health Service Act (42 U.S.C.) by collecting data on the extent, nature, and determinants of common and acute illnesses. Eating disorders are acute and common illnesses, taking the life of one person every 62 minutes.[1]

A. Eating Disorders Are Common, Serious Mental Illnesses Co-Occurring with Medical Complications, Substance Use Disorder, and Obesity

Eating disorders are a very serious mental illness, having the highest mortality rate of any psychiatric illness.[2] Over 30 million Americans experience a clinically significant eating disorder during their lifetime[3], affecting individuals of all ages, races, genders, ethnicities, socioeconomic backgrounds, body sizes, and sexual orientations.[4] While eating disorders can be successfully treated with interventions at the appropriate durations and levels-of-care, only one-third of those with eating disorders receive any medical, psychiatric, and/or therapeutic care.[5]

Eating disorders, including the specific disorders of anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant/restrictive food intake disorder, and other specified feeding or eating disorders, are complex, biologically based illnesses with a strong genetic component and psychosocial influences.[6]

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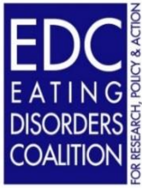
[1] The Eating Disorders Coalition for Research, Policy & Action thanks Scott J. Crow, MD, and Sonja Swanson, PhD, for their diligence and dedication in researching and compiling these latest statistics on the mortality rate. September 25, 2014.
[2] Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. *Archives of General Psychiatry*, 68(7), 724-731.
[3] 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. *Biological Psychiatry*, 61(3), 348-358.
[4] Le Grange, D., Swanson, S. A., Crow, S. J., & Merikangas, K. R. (2012). Eating disorder not otherwise specified presentation in the US population. *International Journal of Eating Disorders*, 45(5), 711-718.
[5] American Psychiatric Association. (2006). *Practice guideline for the treatment of patients with eating disorders (3rd ed)*. Washington, DC: American Psychiatric Association; 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. *Biological Psychiatry*, 61(3), 348-358.
[6] American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, D.C: American Psychiatric Association.



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In addition to the psychological aspects of eating disorders, a high number of medical complications also co-occur in people affected by eating disorders. Eating disorders are associated with a range of medical complications including the cardiovascular, gastrointestinal, musculoskeletal, dermatologic, endocrine, hematological, reproductive, and neurological systems.[7, 8] Severe complications can emerge at any time during the course of illness and can delay/prevent healthy childhood and adolescent development. Additionally, half of people with eating disorders have co-occurring substance use disorder.[9]

One of the biggest misconceptions is that eating disorders are rare and occur only in underweight individuals, often preventing early detection and diagnosis among individuals with overweight or obesity. Although weight loss/very low body index is a defining criteria of anorexia nervosa, it is the exception and not the rule for eating disorders, with less than 1% of the population experiencing anorexia nervosa.[10] On the contrary, individuals with bulimia nervosa and binge eating disorder can be normal weight, overweight, or obese; and have high prevalence.[11] For example, 5% of the population (16 million people) are affected by binge eating disorder, and 81% of individuals with binge eating disorder have overweight or obesity.[12]

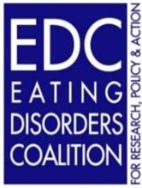
B. Including Questions on Eating Disorder Signs and Symptoms Falls Within the Statutory Scope of NHIS and Would Directly Benefit Researchers Across the Nation

Congress enacted the National Center for Health Statistics to conduct and support statistical and epidemiological activities to improve the effectiveness, efficiency and quality of health services in the United States. *42 U.S.C. § 306(a)*. Specifically, the National Center for Health Statistics is required to collect statistics on the "extent and nature of illness and disability…including the incidence of various acute and chronic illnesses" and "determinants of health". *42 U.S.C. §306(b)(1)*. Between 1991-2015, the CDC through the National Center for Health Statistics recognized the authority and need regarding the acute illness of eating disorders, and included questions on the signs and symptoms of eating disorders within the mandatory section of the YRBSS. NHIS recognizes itself as the primary source of information on the nation's health, covering key topics of national importance including medical conditions, allowing researchers to monitor the progress towards national health objectives, evaluate health policies and programs and track changes in health behaviors and health care use. Further, it would be within the statutory authority and the scope of NHIS to survey families across the nation on signs and symptoms of eating disorders to ensure we have a full view of the nation's health as prescribed within the NHIS scope.

C. Recommendations for Signs and Symptom Questions for Eating Disorders

We recommend that survey items be added to the NHIS questionnaire that were used on the Youth Risk Behavioral Surveillance System questionnaires for many waves before 2015, in

[7] Westmoreland, P., Krantz, M. J., & Mehler, P. S. (2016). Medical complications of anorexia nervosa and bulimia. *Am J Med*, 129(1), 30–37.
[8] 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.
[9] National Center on Addiction and Substance Abuse at Columbia University. (2003). *Food for thought: substance abuse and eating disorders* http://www.centeronaddiction.org/addiction-research/reports/food-thought-substance-abuse-and-eating-disorders
[10] Forney, K. J., Brown, T. A., Holland-Carter, L. A., Kennedy, G. A., & Keel, P. K. (2017). Defining "significant weight loss" in atypical anorexia nervosa. *Int J Eat Disord*, 50(8), 952-962.
[11] Duncan, A. E., Ziobrowski, H. N., & Nicol, G. (2017). The prevalence of past 12-month and lifetime DSM-IV eating disorders by BMI category in US men and women. *Eur Eat Disord Rev*, 25(3), 165-171.
[12] 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. *Biological Psychiatry*, *61*(3), 348–358. http://doi.org/10.1016/j.biopsych.2006.03.040



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addition to items that are used on the questionnaires for Project EAT[13, 14] and Growing Up Today Study,[15] both major U.S. prospective cohort studies funded by the National Institutes of Health. The items we recommend are:

1) "How would you describe your weight?" [Response options: Very underweight; Slightly underweight; About the right weight; Slightly overweight; Very overweight]
2) "What are you trying to do about your weight?" [Response options: Lose; Gain; Stay the same; I'm not trying to do anything about my weight]
3) "During the **past 30 days**, did you go without eating for 24 hours or more (also called fasting) in order to lose weight or to keep from gaining weight?" [Yes/No]
4) "During the **past 30 days**, did you take any diet pills, powders or liquids without a doctor's advice to lose weight or to keep from gaining weight (do not count meal replacements such as Slim Fast)?" [Yes/No]
5) "During the **past 30 days**, did you vomit to lose weight or keep from gaining weight?" [Yes/No]
6) "During the **past 30 days**, did you take laxatives to lose weight or keep from gaining weight?" [Yes/No]
7) "During the **past 30 days**, did you take diuretics (sometimes called water pills) to lose weight or keep from gaining weight?" [Yes/No]
8) "Sometimes people will go on an 'eating binge,' when they eat an amount of food that most people would consider to be very large, in a short period of time. In the **past 30 days**, how often did you go on an eating binge? [Never; 1-3 times; Once a week; More than once a week]

- **IF RESPONSE MORE THAN NEVER**: "Did you feel out of control, like you could not stop eating even if you wanted to stop? [Yes/No]

[13] Neumark-Sztainer DR, Wall MM, Haines JI, Story MT, Sherwood NE, van den Berg PA. Shared risk and protective factors for overweight and disordered eating in adolescents. Am J Prev Med 2007; 33(5): 359-369.
[14] Neumark-Sztainer D, Wall M, Guo J, Story M, Haines J, Eisenberg M. Obesity, disordered eating, and eating disorders in a longitudinal study of adolescents: How do dieters fare 5 years later? J Am Dietetic Assoc 2006; 106: 559-568.
[15] Sonneville KR, Horton NJ, Micali N, Crosby RD, Swanson SA, Solmi F, Field AE. Longitudinal associations between binge eating and overeating and adverse outcomes among adolescents and young adults: Does loss of control matter? JAMA Pediatr 2013; 167(2): 149-155.