**Understanding Service Utilization for Individuals Struggling with Eating Disorders**

**Short Study Title: *Eating Disorder Service Utilization***

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**Protocol version date: *June 16, 2017***

# Protocol Synopsis

This research is concerned with understanding the profile of individuals currently struggling, or who have struggled with eating disorders (EDs), and the patterns of Island Health service utilization among these individuals on Vancouver Island. Our intention is to investigate the prevalence of anorexia nervosa (AN), bulimia nervosa (BN), and eating disorders not otherwise specified (EDNOS; e.g., binge eating disorder), and to further explore various demographic, psychiatric, and other health issues in this population. Along with this descriptive investigation, this research is concerned with understanding the patterns of Island Health service engagement for this population. More specifically, we aim to model risk factors associated with outcomes such as suicidality, self-harm, and malnutrition resulting in hospitalization, and patient encounters with crisis-response teams and short-term assessments and treatments, and to examine the efficacy of services provided for individuals with EDs at reducing these outcomes.

# Background & Rationale

Eating disorders (EDs) are a major health concern for Canadians – young women in particular. More specifically, anorexia nervosa (AN) is believed to have one of the highest mortality rates of all mental illnesses, as 10% to 15% of individuals die from health problems associated with their disorder, or from suicide (Sullivan, 2002). Meta-analytic estimates suggest that 3% of women will struggle with an ED at some point during their lifetime (Arcelus et al., 2011). Although prevalence rates are significantly lower for males, some researchers and clinicians believe that incidence rates for both sexes are on the rise (Hudson et al., 2007).

Characterized by a refusal to maintain a healthy body weight, AN often results in cardiovascular problems, hypothermia, and fertility problems among women (Palla & Litt, 1988). Cycles of binging and purging are indicative of bulimia nervosa (BN), which yields lower mortality rates than AN, but is roughly three times more common (Arcelus et al., 2011, Keel et al., 2003). Individuals diagnosed with an ED are more likely to exhibit disordered alcohol use (Bulik et al., 2004), comorbid mental illnesses (e.g., depression, anxiety disorders, personality disorders; Braun et al., 1994), and both self-harm and suicide attempts (Sansone & Levitt, 2010).

To date, most research on EDs has focused on prevalence, covariates, and predictors of mortality. However, most previous research has been limited in scope (i.e., specifically focusing on prevalence rates, or on one type of health outcome or comorbid psychiatric illness). While this research has provided the necessary foundation for our understanding of ED prevalence and risk factors, a more encompassing research design could allow us to better understand how these individuals access resources within the health care system, how potential risk factors may moderate these interactions, and whether certain services are effective at improving health outcomes. Indeed, some researchers have called for studies that utilize electronic health records to create a more comprehensive understanding of the dynamic nature of ED trajectories and interactions with the health care system (Arcelus et al., 2011). Similarly, most research to date has focused on predictors of mortality, but further research is warranted to investigate factors associated with more common events, such as hospitalizations resulting from self-harm or malnutrition.

# Objectives

This research is concerned with understanding the characteristics of the Vancouver Island population who are, or have at some point in time, struggled with EDs, and to create a more complete picture of how this cohort interacts with the service system as a whole. This research is guided by prior research on ED prevalence and associated outcomes, and involves two primary objectives:

1. To provide a descriptive understanding of the population of individuals struggling with EDs on Vancouver Island (e.g., age at ED diagnosis, prevalence of AN and BN, severity of ED, comorbid diagnoses, substance use, BMI at onset and over time, frequencies and patterns of service engagement).
2. To investigate risk factors for suicidality, self-harm, and malnutrition resulting in hospitalization, and to investigate the effectiveness of ED-specific services in reducing the likelihood of these outcomes. We also intend to examine patient encounters with crisis-response units and short-term assessment and treatment services.

# Major Research Hypothesis and Associated Research Questions

*Research Questions*

* How do ED prevalence and incidence rates compare to other provincial, national, and international estimates?
* How do comorbidity rates for other psychiatric diagnoses, health problems, and substance use compare to other published estimates?
* Broadly speaking, how are individuals struggling with EDs utilizing Island Health services? How do individuals accessing ED treatment services differ between individuals who have and have not received clinical ED diagnoses?

*Main Hypotheses*

* Patients demonstrating a lower BMI at ED diagnosis, and/or exhibiting disordered alcohol use will be at an increased risk for hospitalization from self-harm and malnutrition.
* Patients who engage in eating disorder treatment services will be at a reduced risk for hospitalization from self-harm and malnutrition, and a reduced risk for encounters with crisis-response teams and short-term treatment programs.

# Study Approach, Design

**Design**

The sample will include all individuals who have received an eating disorder diagnosis at some point in their lifetime (ICD-10 Code: F50), and/or all individuals who have accessed eating disorder treatment services, dating from 2002 to present. All encounters that these individuals have had within the Island Health system will be included, along with available Mental Health Minimum Reporting Requirement data on all individuals in this sample (for information on suicidality, substance use, and other relevant mental health covariates). We expect the majority of the sample to be females between 10 and 24 years of age. This research is solely concerned with the exploration and analysis of this data.

**Analyses**

This research is largely exploratory, and much of the analysis will involve simple descriptive approaches. With regard to the research questions regarding the risks and likelihood associated with certain outcomes (e.g., self-harm, crisis-response unit encounters), generalized linear mixed models will be used to account for the nested structure of the data (i.e., multiple encounters for each individual).

**Data Elements**

This research will utilize clinical encounter-level data from the Island Health data warehouse for a cohort whose membership is defined by having had an ED diagnosis, or having had any encounters with eating disorder treatment services. This research will also include available Mental Health Minimum Reporting Requirement data for these individuals.

**Study Limitations**

Extensive coordination and communication between researchers and health service professionals will be required when analyzing this data to accurately and effectively conceptualize concepts of interest (e.g., self-harm hospitalizations, levels of crisis-response interventions). If there is a substantial amount of missing data at certain time periods (i.e., prior to consistent electronic recording of certain health service information), then data from this time period may have to be removed for analysis. Lastly, depending on the number of individuals in this data, power to test between-person research questions may be limited.

# Data management

* Clinical encounter-level data from the Island Health data warehouse for a cohort whose membership is defined in terms of ED diagnosis, and/or having had any interactions with any eating disorder treatment services, as well as available Mental Health Minimum Reporting Requirement data for these individuals.
* All dates will be expressed in terms of duration (days) from day 0.
* All data elements reviewed against the Safe Harbour list of identifiers; all Safe Harbour de-identifiers will be marked or deleted; keys to link the de-identified data to the dataframe with identifiers will not be disclosed to the researchers.
* Researchers will only have access to de-identified data.

# Consent, Protection of Privacy

Technical Controls – *The use of firewalls and encryption where possible*

Administrative Controls – *Privacy agreements between the University of Victoria, Island Health and all members of the research team*

Data De-identification Controls – *For this Eating Disorder Service Utilization project, the Safe Harbour de-identification methodology will be employed as the reference standard for deeming the research data is free from personal information*

# Data retention

Will comply with the University of Victoria and Island Health Policies, and any additional conditions set forth in accordance with TCP2.

# Publication of Results

Findings will be shared through conference presentations, publication in academic journals, and through sharing of a series of data visualizations with Island Health.

# References

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*, 724-731.

Braun, D. L., Sunday, S. R., & Halmi, K. A. (1994). Psychiatric comorbidity in patients with eating disorders. *Psychological medicine*, *24*, 859-867.

Bulik, C. M., Klump, K. L., Thornton, L., Kaplan, A. S., Devlin, B., Fichter, M. M., ... & Mitchell, J. E. (2004). Alcohol use disorder comorbidity in eating disorders: a multicenter study. *The Journal of clinical psychiatry*, *65,* 1000-1006.

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*, 348-358.

Keel, P. K., Dorer, D. J., Eddy, K. T., Franko, D., Charatan, D. L., & Herzog, D. B. (2003). Predictors of mortality in eating disorders. *Archives of General Psychiatry*, *60*, 179-183.

Palla, B., & Litt, I. F. (1988). Medical complications of eating disorders in adolescents. *Pediatrics, 81*, 613-623.

Sansone, R. A., & Sansone, L. A. (2010). Personality Disorders as Risk Factors for Eating Disorders Clinical Implications. *Nutrition in Clinical Practice, 25*, 116-121.

Sullivan, P. F. (2002). Course and outcome of anorexia nervosa and bulimia nervosa. *Eating disorders and obesity: A comprehensive handbook*, *2*, 226-232.