

Additional background information on ExpBoD

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I. Background

Consider three groups of Danish adults with breast cancer, alcohol use disorder, or stroke. Despite having similar population-level disease burden in 2017,^{5,16} experienced burden likely varies depending on social and cultural norms, welfare and healthcare system, among other factors. Anecdotally breast cancer patients have suggested lower **psychological burden** due to receiving greater level of sympathy. One study found that depression is common in patients with stroke, but it is unclear how it compares to other diseases.¹⁷ Having alcohol use disorders in Denmark may not lead to greater psychological burden since alcohol use is well accepted socially, but may be associated with more detrimental **social effects**, such as its impact on marriage status and children's well-being.^{18,19} **Economically**, stroke and alcohol use disorders are more common among working men, leading to greater economic impact than breast cancer that predominantly affect older women.^{12,20} See Figure 1 for graphical illustration.

Previously, the Nordic Burden of Disease Collaborators studied disease burden across the five countries but its focus was restricted to health metrics.²¹ Beyond traditional metrics, the economic impact, utilization of health services, and self-reported health outcomes are the most frequently studied in the Nordics.⁵⁻¹³ In reviewing the literature, we have identified two gaps, both of which will be addressed by ExpBoD: (1) **Limitation in scope**: Existing single disease/dimension studies cannot be compared due to differences in methodology and use of inconsistent data sources. (2) **Limitation in statistical methodology**: Many studies apply the same matched-cohort design, controlling for the same covariates without providing rationale for the choice of the method and covariates, how study time periods were selected or time-varying covariates were handled.^{12,22} Sensitivity analyses on methods and parameters are seldomly presented. Furthermore, the results cannot be compared across diseases due to differences in the control groups.⁵ These studies have provided insightful evidence but their narrow perspectives, methodological approaches, and weak links to

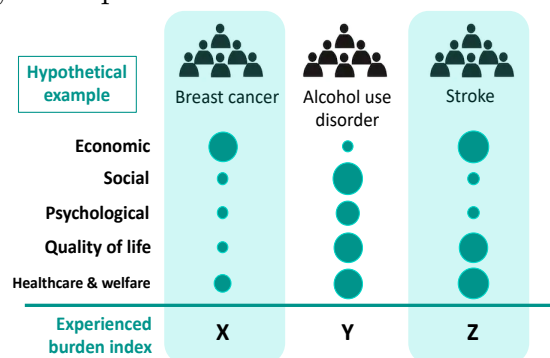


Figure 1. A graphical illustration of the main results

policymaking have limited their real-life impact. ExpBoD will address both limitations: limitations in **scope** addressed by Objectives 2 and 3 and **statistical methodology** by Objective 1 (described below).

II. Objective: research question and potential hypotheses

Main research question: What is the experienced disease burden among patients with breast cancer, alcohol use disorder, and stroke, respectively? Experienced disease burden is defined as the socio-economic, psychological, healthcare and welfare impacts due to the disease.

Secondary research questions: (1) What are the strengths and weaknesses of existing statistical methods to measuring non-health disease impacts in registry-based studies? (2) How should we facilitate meaningful comparisons of experienced burden across diseases, taking into account the socio-economic and demographic differences across patient groups?

Hypotheses: (1) Even if the levels of disease burden (measured in traditional metrics such as years of life lost or prevalence) are similar, the non-health impacts vary widely; (2) Experienced burden can be systematically measured using existing data sources and compared across diseases; (3) Certain statistical approaches and parameter selection are more suitable for measuring experienced burden.

Objectives: (1) Assess statistical methods to identify the most appropriate methodology, (2) Systematically estimate disease impact across dimensions and diseases, conduct sub-group and decomposition analyses, (3) Create a composite index for experienced burden.