Protocol for variables from Diabase

The overall aim of this project is to identify the contributions of family and early life determinants on the development, management and care of diabetes and the diseases that may arise following a diabetes diagnosis, under a life-course framework. The justification for requesting data on multiple disease areas directly follows the primary aim of this project. We investigate this aim focusing on diabetes as the central disease of interest. Diabetes consists of different subtypes (Type 1, Type 2, LADA, MODY, gestational diabetes, secondary diabetes, rare monogenic forms) each with a different set of risk factors, presentation and pathophysiological characteristics. The familial and social effects that are the subject of this project are likely to be different for each of these diabetes subtypes. E.g. for some types of diabetes, caused predominantly by auto-immune mechanisms, familial associations to other auto-immune diseases are more likely than for type 2 diabetes, which is driven to a strong degree by obesity, low physical activity and insulin resistance.

All forms of diabetes have an increased blood glucose level as their central hallmark, and are associated with major and minor complications. The vascular complications are generally subdivided into large-vessel disease (macrovascular) and small-vessel disease (diabetic retinopathy, neuropathy nephropathy). The occurrence of these complications is not dependent solely on the elevated glucose levels, but also on disturbance of other metabolic risk factors, familial predisposition and pre-existing conditions.

An important feature of diabetes is that it can be undetected for several years, and that the diabetic complications can sometimes be the first presentation of the disease. In order to study the occurrence of diabetic complications in the context of family we need to assess the complication status for all traditional and novel diabetic complication.

Adequate treatment of diabetes depends on long-term engagement and motivation of the patient for self-management of different aspects of the disease. The capacity to respond adequately to this challenge depends to a large degree on socio-economic status, including the degree of social support in the direct environment surrounding the patient. These effects occur in interaction with other chronic conditions, including mental health conditions.

The justification for the requested list of variables falls into four categories:

1. Diagnosis of diabetes itself, in all its forms and subtypes.
2. Conditions that are an established cause of diabetes, and diseases which have an emerging association with diabetes, which we wish to investigate.
3. Major and minor complications and other consequences / signs of diabetes.
4. Conditions needed to adjust our analyses for the simultaneous occurrence of other chronic health problems (co-morbidity)

Complications relevant to Diabase are eye diseases. The major eye complications of diabetes include diabetic retinopathy and macular edema. There are also minor complications like cataracts and glaucoma. Furthermore, infections of the eyelid and adnexa are also seen.

Since we will be studying associations of various exposures (for instance, family environment while growing up) on the risk for developing diabetes, we need to identify who develops diabetes in the Danish registers. We use algorithms developed within Steno for classifying individuals with diabetes (e.g. see http://bendixcarstensen.com/DMreg/DMreg2018.pdf). These algorithms need specific variables from Diabase.

We also want to study what exposures (for instance, whether other family members have diabetes) increase the risk of developing complications (like retinopathy) for those who already have diabetes. We rely on the work of colleagues to determine which variables they used to classify and study these complications, which we have requested.

The other categories rely on classifying complications through the use of algorithms so that we may adjust for them or include them in sub-analyses.

Budget

The cost of the application to access data from the registers as well as any associated costs is covered by Steno Diabetes Center Aarhus.