



Supporting Patients through Education & Research

Lay Summary - An Epidemiological Study of Systemic Sclerosis and its association with Cancer in the UK using the Clinical Practice Research Datalink (CPRD) – Dr John D Pauling, Dr Anita McGrogan, Dr Alison Nightingale & Professor Neil McHugh

Epidemiological studies help us understand patterns of diseases in the population and can sometimes help us to understand why these diseases occur and how they can be prevented. Previous epidemiological studies have suggested that the number of patients with systemic sclerosis (SSc) in the UK is significantly lower than in the US, Australasia and Europe. Limitations in earlier study design may have accounted for these findings. A fresh analysis of the number of patients in the UK who either have (prevalence) and are getting (incidence) SSc is desirable as this shall allow us to monitor changes in the disease trends (which could help us understand causative factors in SSc development) and will allow us to accurately plan the service needs of patients with SSc attending UK hospitals.

Nearly 1 in 10 patients with SSc are also unfortunate enough to experience a diagnosis of cancer either before or after their diagnosis of SSc. It has been suggested that cancer might cause SSc in some patients, whereas in others the risk of cancer is raised due to either the disease process itself or the treatments we use to treat it. Additional work is needed to better understand the burden of cancer in SSc and this study shall help us understand the risk of cancer occurring in SSc, the specific cancers we should look out for in SSc and the burden of mortality from cancer in SSc.

The proposed epidemiological study will examine healthcare information from nearly 20 million UK residents and give us up to date figures on the likely number of patients in the UK with systemic sclerosis (a feat not attempted in nearly 30 years) and whether the number of new patients with this disease is rising or falling. We will then examine the relationship between SSc and cancer by comparing people with SSc (and cancer) with people of a similar age and gender who don't have SSc (or cancer). We want to better understand which patients with SSc get cancer and when. We will look closely at the relationship between the time of SSc diagnosis and cancer to build on recent work that has proposed cancer as a key driver in the development of systemic sclerosis. This will allow us to develop (using results obtained from this work) evidence-based surveillance programmes for looking for cancer in high-risk patients. We believe this work will help us understand important causes of SSc in some people. It will improve survival in SSc by raising awareness of the relationship between SSc and cancer and is the first step to developing health programmes that shall identify cancer earlier when it strikes to ensure prompt treatment and better outcomes.