

Lay Summary – Dr Timothy Card

In 2001 NACC funded the purchase of a data set by the applicant for this grant to study mortality and osteoporotic fracture risk in IBD. This data set was able not only to permit these studies, but has also allowed the examination of the safety of azathioprine use (in relation to cancer risk) and the risks of pulmonary embolism and deep vein thrombosis (venous thromboembolism – VTE) in IBD, among other projects. Over the last 9 years not only has more data accumulated in the GP database from which the dataset was drawn, but also the database has been linked to other data from hospitals and the office of national statistics (for a proportion of cases). In addition methodology has been developed to reliably link parent and child data to permit better examination of pregnancy outcomes, and hospital data (Hospital Episode Statistics) have become more reliable permitting further examination of inpatient events. These developments mean that by obtaining new downloads of anonymised computerised records from both GP and hospital sources a large number of additional questions can now be usefully addressed by these data. Though there are many projects which could in time be undertaken using this data, we are requesting funding to conduct the following specific analyses.

1. Though we know that IBD became far more common over the second half of the twentieth century, it is far less certain whether this increase continues, and in what ways any increase may vary by age, gender, region or social class. The first fairly simple study we will conduct is to ascertain this information in a dataset which has now been collected in a reasonably uniform manner for over 20 years. This information will be of great value in the planning of health services for IBD patients.
2. The recent pronouncements by NICE respecting anti TNF agents have been noteworthy for many reasons. To an epidemiologist, one of these is that the best data NICE could find to describe the natural history of IBD was from a small population in the USA. We will use the records available to characterise the natural history of IBD among UK patients in a number of ways, but with particular reference to the proportion of patients remaining under regular follow up, receiving steroids, and undergoing surgery. This information will permit more accurate assessment of the potential for benefit from new therapies.
3. It has been known for many years that IBD patients when in hospital with a flare of their disease are at high risk of VTE. We have recently by analysis of the dataset previously funded by NACC shown evidence that this risk is also high during flares of disease out of hospital. The great weakness of this study was that we were unable to define when people were in and out of hospital precisely (which means we cannot be sure of exactly how high the risk is). We wish to repeat this study using the linked hospital and GP data now available. This is important because if the risk is high we should consider methods of preventing VTE during flares out of hospital.
4. In a disease affecting young adults, reproductive issues are always an emotive subject of great interest to the young patients involved. Though we do know something about reproductive effects for some subsets of IBD patients, it is less clear to what degree fertility overall is affected, and precisely what the interplay between drugs disease and pregnancy is. We propose to study maternal, and linked maternal child records to determine fertility rates, and the degree to which pregnancy affects disease activity as well as how the drugs used to treat it affect pregnancy outcome. As some outcomes (such as congenital malformation) are rare, we may well be unable to give absolute answers in all these areas, but these data will make an important contribution in this area which is very difficult to study.