Background to data files.

The rationale for collecting this data is based upon the Edinburgh surveillance strategy for HCC (hepatocellular carcinoma), the commonest form of primary liver cancer (cancer originating in the liver).

Following recommendation changes in the early 2010’s we collected retrospective data on all patients having AFP measured in their blood as a marker of liver cancer. AFP is a protein secreted by many liver cancers which may be helpful in their early detection by a blood test. These patients are all deemed at risk of developing HCC by a specialist and hence entered into HCC surveillance. Of this large cohort (>1500 patients) who were being surveyed in 2009 (not necessarily entered into surveillance in 2009) a number have subsequently developed HCC. The two files (1+2) reflect these two populations – surveyed but without developing cancer and surveyed and developed cancer. These files are respectively:

*Screening cohort for MSc project (1)*

*HCC in screening for MSc project (2)*

There were strict criteria for entry into this 2009 cohort. They are given in the publication Bird et al. PLOS One 2016 (<http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0156801>). It is important to bare in mind that just because someone was in surveillance in 2009 does not necessarily mean that they remained in surveillance throughout (some drop out or even out and back in) nor does it mean that they are still alive. However we are confident that they have not developed HCC. The reason for this is we have exhaustively looked through all cases of HCC since 2009 and matched them between the databases. The cases that have developed HCC are in the second file, however they also contain patients who were not in the 2009 surveillance cohort (see column H). Patients who were originally in the 2009 cohort are marked with a “y”.

Patients at risk of liver cancer have some form of liver disease. Most common forms of liver disease in the UK are

Alcoholic Liver Disease (ALD) – related to long term alcohol excess

Non alcoholic fatty liver disease (NAFLD) – related to obesity

Hepatitis C virus infection – HepC/HCV

Hepatitis B virus infection – HepB/HBV

Haemochromatosis – a genetic condition causing iron accumulation within the liver

Autoimmune diseases where the immune system reacts abnormally against the body; examples are (PBC, PSC, AIH)

Other rare causes.

Often these conditions can be multifactorial e.g. it is possible to have liver disease caused by alcohol compounded by being obese or vice versa.

HIV does not itself cause liver disease (although the drugs to treat it can), but HIV through suppressing the immune system can lead other causes to be more aggressive at causing cancer.

Data collection.

Data has been retrieved (manually in many cases by painstakingly going through individual patient notes) for individual cases. Each separate case has a unique identifier (1 – column B; 2 – column A). Each case has had all AFP values throughout collected together with their date. On those dates the patient was alive. It is reasonable to assume that once AFP has stopped being collected they have been ‘lost to follow up’ (either death, moved house, changes in circumstances, or potentially are deemed no longer at risk of HCC or suitable for surveillance e.g. not attending, frailty).

It is fair to assume that the date of the first AFP test was the date that person was deemed at risk of HCC enough to enter HCC surveillance. This is not always exactly the same but is typically once someone has cirrhosis of the liver detected.

If a patient develops HCC then it is fairly safe to say that we know about it. However not all liver cancers will present at the same stage; to say some may be small and localised and treatable, whilst others may be larger, more aggressive and have spread- and be untreatable.

The date of a diagnosis of HCC is defined at the date that a test was performed which confirmed the presence of the tumour. This can either be scanning (CT or MRI) or a biopsy (sampling a small piece of the tumour or removing a large piece at surgery). After diagnosis some tumours will have treatments which can cure or remove part of the tumour. These treatments may affect the serum AFP value.

For each patient the principle aetiology (cause of liver disease) is recorded, but this may be followed by other additional contributing aetiologies.