

Familial gastric cancer study



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The **Familial Gastric Cancer Study** was set up in 1997 by Professor Carlos Caldas originally to collect information and blood samples from families with clustered cases of gastric cancer in the UK.

Currently, the study aims to:

- Identify those individuals who fit the criteria for Hereditary Diffuse gastric cancer and provide long-term follow-up of CDH1 mutation carriers.
- Collect detailed information (clinical, psychological, physiological, nutritional, metabolic and lifestyle) on individuals undergoing clinical testing for mutations in order to assess mental symptoms and wellbeing at the time of genetic testing, endoscopy screening / surveillance and pre / post prophylactic total gastrectomy (PTG) surgery. Validated questionnaires looking at wellbeing and quality of life will be sent out to research participants. These can be filled out as paper questionnaires or via an anonymised online link hosted by Cambridge University.
- Determine the most effective form of endoscopy techniques to detect micro foci of signet ring cells in individuals at high risk of stomach cancer.
- To obtain a detailed family history / family pedigree, blood or saliva + /- gastric tissue samples from participants and family members with a history of 'diffuse' gastric cancer (DGC). This will enable us to search for new genes in families who are CDH1 negative

or who have a strong family history of gastric cancer but have tested CDH1 negative or have not been offered genetic testing.

Individuals who wish to participate in the Familial Gastric Cancer Study must fulfil the criteria for HDGC and provide their written consent. Additional information will be collected about the family history of cancer and pathology confirmations. With consent, we will try to confirm cancers in deceased members of the family, although this is usually done by the referring Genetic centre.

A blood sample or saliva sample (which can be taken at home) will be collected which is stored for DNA analysis for our research. The relevant kit and envelope for return will be sent in the post to be returned to the Research Nurse in Cambridge. Your GP will also be contacted to inform them of your participation in the study

A few people taking part in the study will have an alteration (mutation) in a gene called CDH-1 and the research team would like to collect more information about this. Individuals from families who meet the criteria for Hereditary Diffuse Gastric Cancer and who have undergone clinical testing will be invited to take part in the second part of the study called the **“Hereditary Diffuse Gastric Cancer Registry”**. If consent is given information will be held on the data register which is maintained here in Cambridge. Quality of Life questionnaires will be sent to the individual at regular intervals e.g. following genetic testing, endoscopic screening and before/after surgery. These questionnaires help us to measure the impact of screening and surgery including morbidity, quality of life and the psychological effects of surgery.