

TITLE: Study of the incidence of gastro-intestinal stromal tumours (GISTs) in Scotland

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ABSTRACT:

Introduction: The lack of formal diagnostic criteria, pre-dating the development of immunohistochemical assays for c-kit means GISTs may have been classified as tumours with similar appearances e.g. leiomyoma, epitheloid leiomyosarcoma, leiomyosarcoma or even as sarcoma not otherwise specified. This combined with a low incidence means there is uncertainty about the true prevalence of the disease within the Scottish population. We therefore wished to examine all archived mesenchymal tumours arising along the gastro-intestinal tract, which could potentially be GIST, with an immuno-histochemical (IHC) test to study c-kit expression.

Methods: A retrospective study based on archived pathological records and material from patients with an actual or suspected primary diagnosis of GIST identified from pathological records of Scottish Hospital pathology departments between Jan. 1st 1995 and Dec. 31st 1999. The study will be divided in to two stages;
(1) anonymous confirmation of GIST cases with c-kit IHC. Tumours which are histopathologically consistent with or suspicious of GIST but negative for c-kit will be stained for CD34
(2) collection of patient information of genuine GIST cases after informed consent has been obtained.

End-points: The primary end-point is to establish the incidence of GISTs in the Scottish population. Secondary endpoints will be:
to establish prognostic factors in GIST.
to establish the survival of patients with GISTs in the Scottish population.
to determine the c-kit expression status of patients already diagnosed with GIST.
to establish a register of GIST patients in Scotland.

Results: To date we have assessed the incidence of GIST over a 5 year period in on of 15 health boards in Scotland and are about to start the clinical data collection for these cases. In this region a diagnosis of GIST was already made in all but 1 of 14 of cases, but was confirmed with IHC for c-kit. In this single area the estimated incidence is 7 / million population.

Conclusions: To date we have limited information but based on one single Health Board area the incidence is lower than that seen in other studies [1, 2]. We designed the study based on screen hospital pathology records rather than clinical diagnostic codes and therefore case ascertainment should be high. We shall present additional incidence and clinical data from other health boards at the meeting.

1. Miettinen, M., et al., *Hum Pathol*, 2002. **33**(5): p. 478-83.
2. Nilsson, B., et al., *Cancer*, 2005. **103**(4): p. 821-9.