

C1

Incidence, Prevalence and Survival of Patients with Small Bowel Neuroendocrine Tumors (MGC) Excluding Appendiceal Tumors: A Northern Ireland (NI) Study Over 25 years

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Background: Incidence of MGC is 0.5-1/100,000/year and is said to be rising, perhaps due to improved diagnosis rather than a true incidence increase. Improving survival has been slow to confirm, even with the increase in treatment options in the last decade. ENETS and UKINETS emphasize the importance of patient management in NET specialist centers (NSC) with multidisciplinary team (MDT) input. We have had a NSC since 1978 with an MDT since 2000.

Methods: Data collection used the NI Cancer Registry, NET Clinic records, NI pathology records, Regulatory Peptide Laboratory records and patient clinical notes. MGC was diagnosed by pathology or by syndrome, radiology and biomarkers. Population in NI was obtained from census data. Data 1988-2012 was collected with survival follow up to 6/30/2014

Results: Between 1988 and 2012, 313 individuals with MGC were diagnosed, 335 were included for prevalence calculations. Diagnosis was secured by pathology in 94%. M/F ratio was 52/48.

	1988-1992	1993-1997	1998-2002	2003-2007	2008-2012
NI population in millions	1.56	1.63	1.68	1.72	1.81
MGC Incidence/100,000	0.47	0.5	0.69	0.67	1.14
MGC Prevalence/100,000	2.6	2.91	3.96	5.05	6.38

Survival did not change significantly 1988 to 2012 (5Y periods).

Since 1/1/2000, 199 patients with MGC and survival follow up were identified, 135 attending the NSC. Those surviving <3M were excluded. Comparing survival non-NSC to NSC patients, 1Y survival improved from 72.7% to 95.4.1%, 2Y 46.5% to 81.67% and 4Y 24.4% to 46.5%. On 6/30/2014 62.8% of NSC patients were alive compared to 18.2% of non-clinic patients. To remove age bias patients were age matched for age at diagnosis (+/-6m) NSC and non-clinic patients (60:60 patients). Survival was significantly better in the NSC patient group (Log Rank Test, P<0.019).

Conclusion: In this small insular population, incidence of MGC shows an increase 1988-2012. Survival is significantly improved when patients attend the NSC.