The German neuroendocrine tumour (NET) registry: Epidemiology of neuroendocrine tumours and data quality

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Introduction NET are rare. No epidemiological data of NET are available in Germany. Thus, the AG NET/DGE introduced the German NET Registry in 9/2003. First data of the registry are presented.

Methods A NET specific database was constructed. 5903 specialists (gastroenterology, endocrinology, oncology) were invited to participate. Centres (C) had to treat at least 5 pts with NET to be included in the database. C are grouped according to the number of pts treated: small (SC), medium (MC), large (LC), very large (VLC): 5-10/11-20/21-100/>100 pts, resp. C are visited by 2 study nurses, patient files are analysed and data transferred to the database. Only pts with a diagnosis of NET after 1.1.1999 are included. To evaluate the data quality, data were retrieved from the German NET-Registry database. Data were analysed according to the documentation of diagnosis, histology, imaging, biochemical investigations and therapy

Results As of 10/2006 136 C participate, 13 C have already been visited. All are university clinics (Fig 1). Pts are cared for by specialists of internal medicine, surgeons or by both specialities at one C (Fig 2) 904 pts (452 f), 57 ys (13-87) (median, range) at diagnosis are evaluated. MEN-1 pts (N=30) are younger at diagnosis [45 ys, (24-61), MEN-1 vs sporadic NET, p<0.0001]. Tumours are classified as foregut, midgut, hindgut, cancer of unknown primary (CUP) and no classification available (Fig 3). Functioning tumours are identified in 222 (25%) pts . Mean follow-up is 1y (0-7), with more than 1 visit/pt documented in 72%. Mortality is 8 % during follow-up, with a median survival time of 1 y (0-5) (Fig 4). DataQuality: Diagnosis For the documentation of classification, localisation of the tumour (specific organ or CUP), functionality and time interval between first symptoms and diagnoses (Fig 5). Documentation of functionality was poor (Fig 6). MEN-1 was documented in 30 (3.3%) not documented in 812 (90%),and excluded in 60 (6,7%) Histology Documentation of morphological, immuno-histochemical neuroendocrine markers, mitotic indices, WHO classification of the tumour and invasive behaviour is poor. This is an important finding as therapeutic decisions rely on these data (Fig 7 and Table 1) Imaging: Somatostatin receptor scintigrahy (SRS) was done in 566 (62%) (Fig 8). 349 pts without SRS were classified as foregut, midgut, hindgut, and CUP. SRS in relation to therapy is given in Fig 9. Imaging (sonography, CT, MRT) was documented 3,5 /2,8/1,8 and 1,8 times per pt. in medium, very large, large, and small (SC) centres, rsp. Biochemical investigations were documented at least once per pt. in 619 (69%). Therapy (tx) The first tx was surgery, medical tx, radioreceptor tx, or ablative tx in 651 (72%), 170 (19%), 10 (1%) 8 (0,9%). 65 (7%) pts had no documented tx (Fig 10). Pts were treated with up to 6 different tx. The number of tx correlated positively with the number of pts treated per centre, while the type of tx was evenly distributed.

Fig 1 Participating active centres (N=13) and percent of pts. in each centre (total N=904)

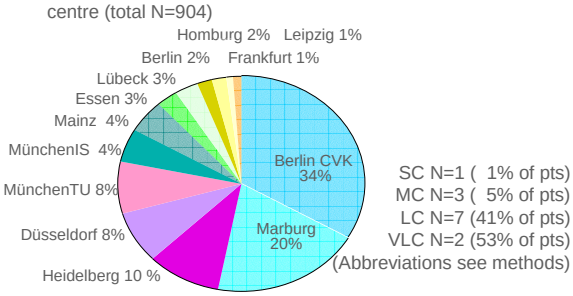
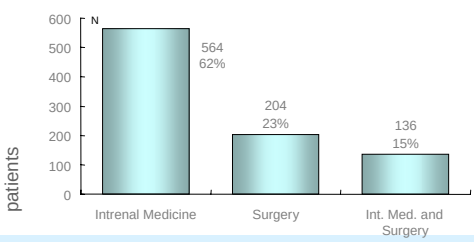


Fig 2 Participating centres N=136 according to medical specialities



Conclusion The German NET-registry is an effective tool to analyse epidemiological data of NET pts. However, as the number of pts included is still rather low, definite data await the inclusion of larger numbers. In addition, the data base reflects the structure of care, provided in Germany. Despite the observational character of the NET-registry changes are already implemented with respect to the organization of patient care. Documentation was almost complete with respect to diagnosis. However, important histological data were poorly documented, as were some imaging procedures considered essential in these tumours. Documentation of different therapies was highest in very large centres. The number of pts per centre did not significantly influence the quality of the documentation. Further information: www.net-register.org

Fig 3 Classification of neuroendocrine tumours (N=904)

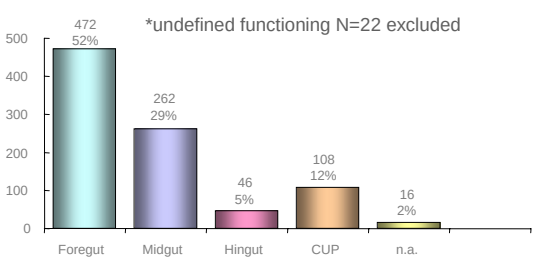


Fig 4 Follow-up (N=904)

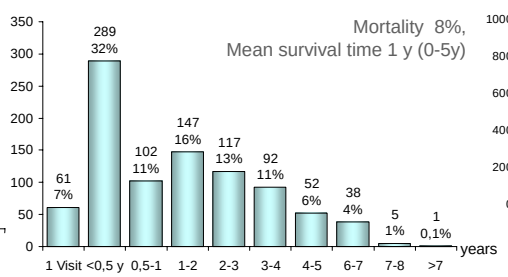


Fig 5 Details documented with diagnosis (in % of pats N=904)

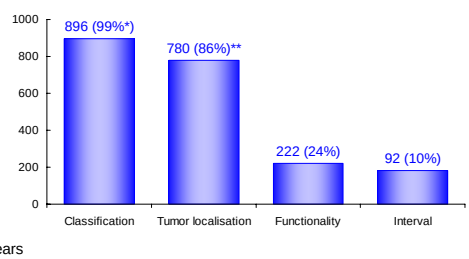


Fig 6 Documentation of functionality

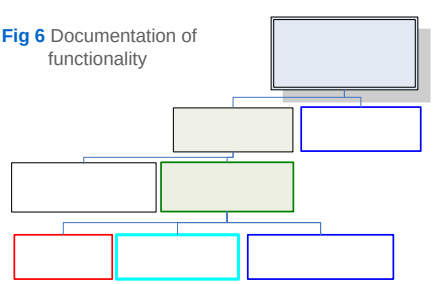


Fig 7 Documented histological data of the primary

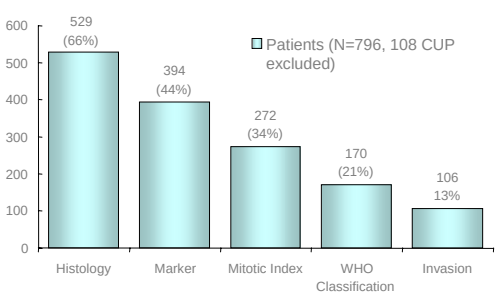


Table 1 Diagnosis in patients without histology

Diagnoses	N=193	%
Foregut (lung, pancreas, duodenum, stomach N=11)	96	50%
Midgut (Ileum, jejunum, coecum, appendix N=5)	52	27%
Hindgut	6	3%
CUP	29	15%
No information available	10	5%
Total	***193***	*100%*

Fig 8 Somatostatin receptor scintigraphy

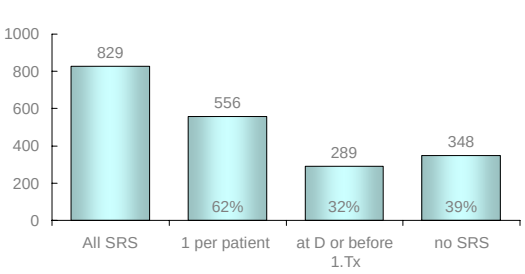


Fig 9 SRS in relation to therapy

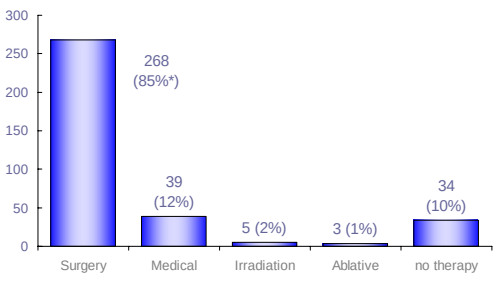


Fig 10 Therapy in percent per centre