



The German neuroendocrine tumour (NET) registry: Quality of Data Documentation

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Introduction In 9/2003 the German NET-Registry was introduced. With 13 centres and 904 pts included, we analysed the quality of data documentation in patients' files of 13 active university centres.

Methods Data were retrieved from the German NET-Registry database. Data were analysed according to the documentation of diagnosis, histology, imaging, biochemical investigations and therapy.

Fig 1 Details documented with diagnosis (in percent of pats N=904)

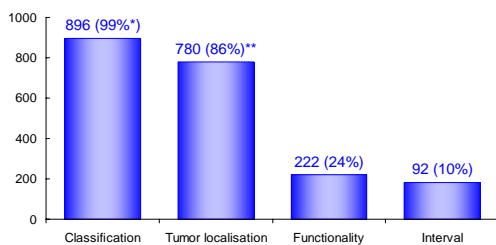


Fig 2 Original classification and corrected data according to tumour localisation

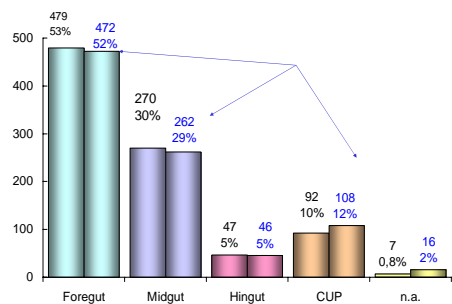
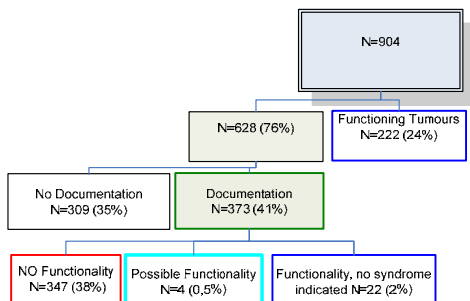


Fig 3 Documentation of functionality



Results Diagnosis For the documentation of classification, localisation of the tumour (specific organ or CUP), functionality and time interval between first symptoms and diagnoses see Fig 1. Fig 2 indicates the original and corrected documentation of tumour classification. Documentation of functionality was poor (Fig 3). 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 4 and Table 1) **Imaging:** Somatostatin receptor scintigraphy (SRS) was done in 566 (62%)(Fig 5). 349 pts without SRS were classified as foregut, midgut, hindgut, and CUP. SRS in relation to therapy is given in Fig 6 **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, resp. 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. 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 4 Documented histological data of the primary tumour

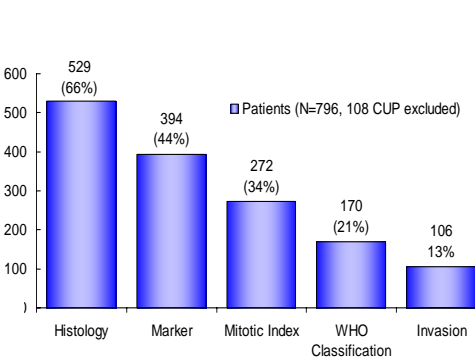


Table 1 Diagnosis in patients without histology

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

Conclusion 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 5 Somatostatin receptor scintigraphy

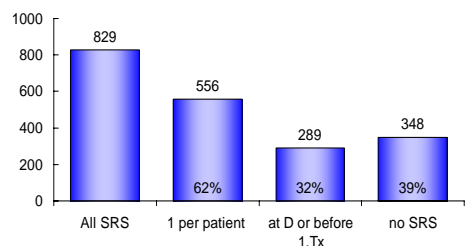


Fig 6 SRS in relation to therapy

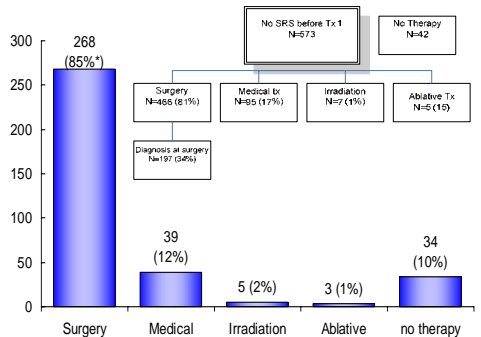


Fig 7 Therapy in percent per centre

