

P069. Patient Perception of Provision of Care for Multiple Endocrine Neoplasia Disorders In the United Kingdom Compared to Other Countries within Europe

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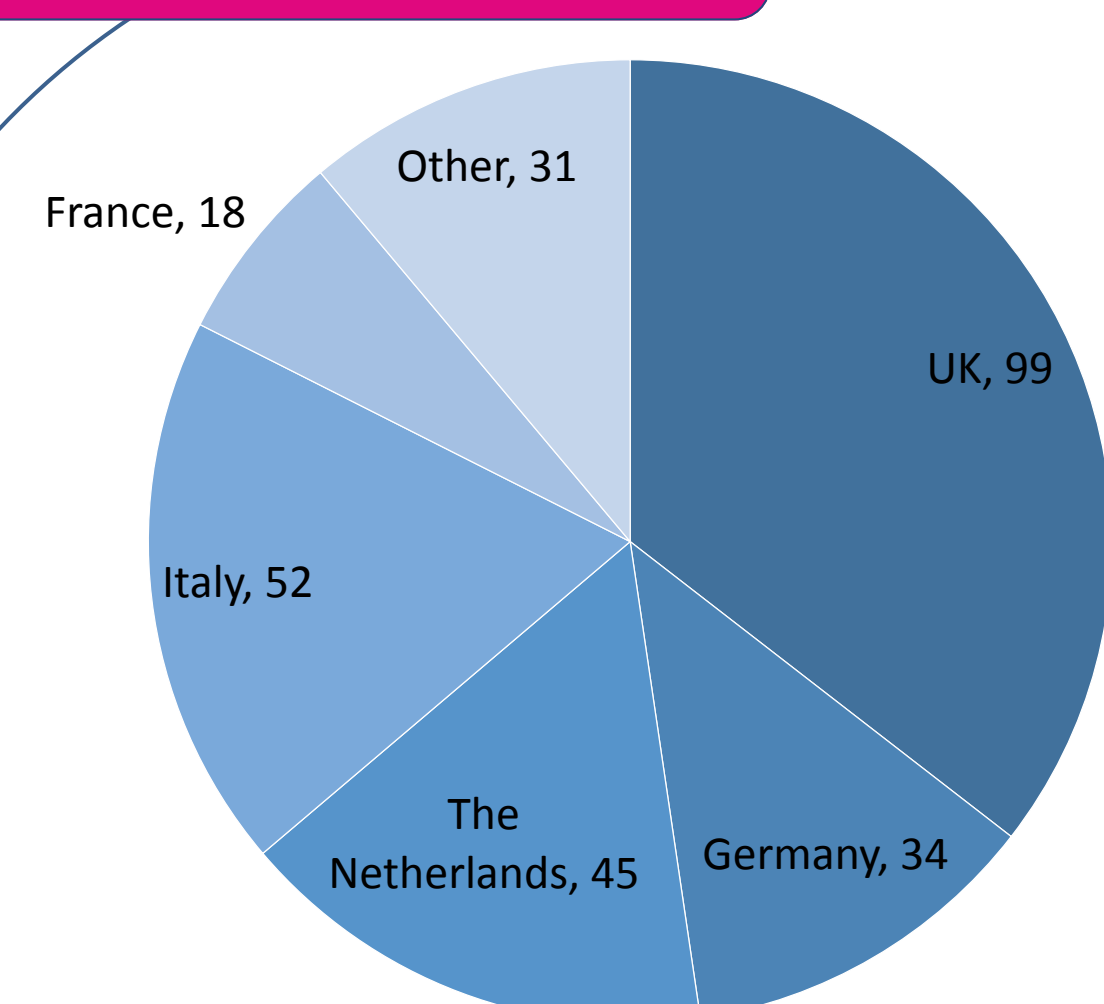
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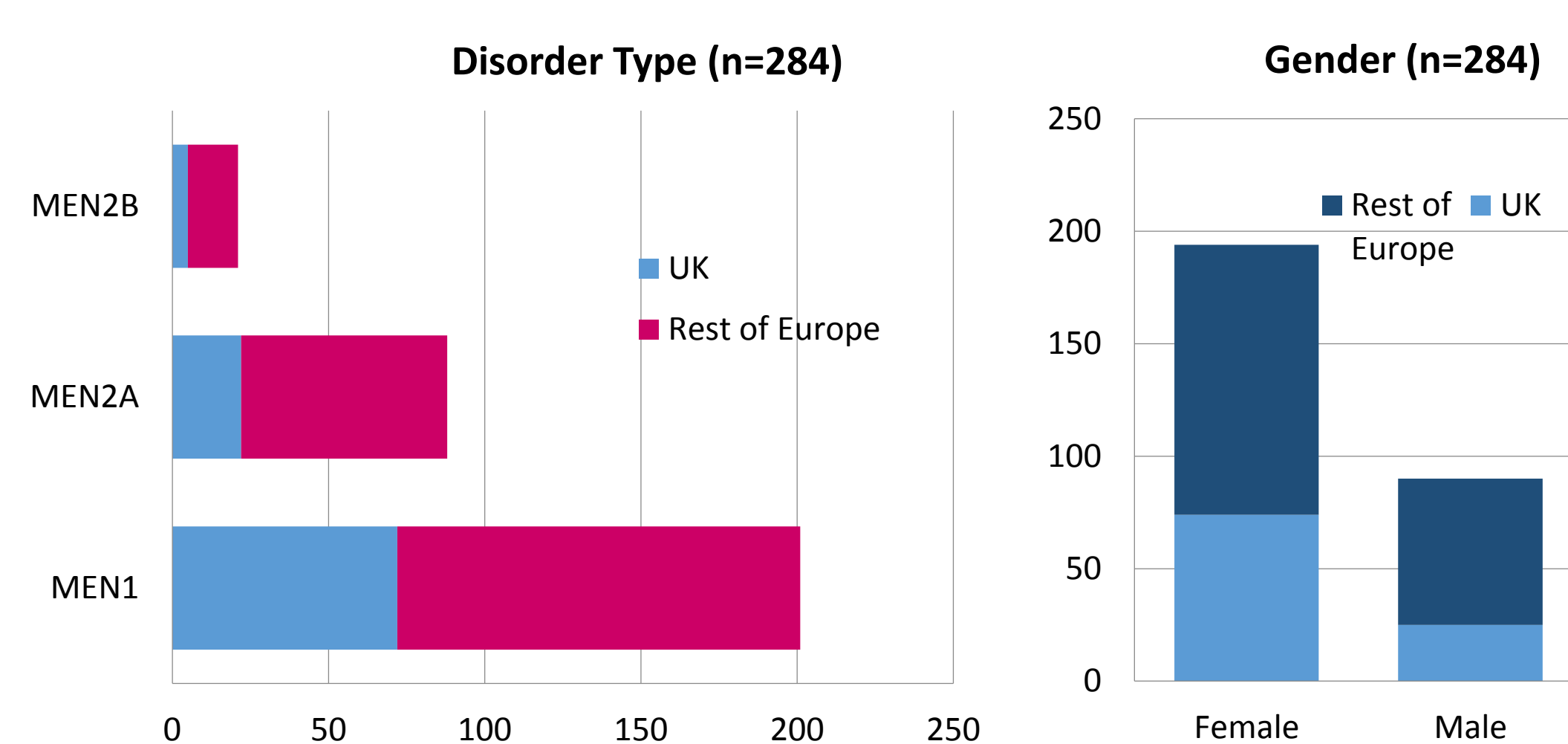
METHOD

EMENA is an alliance of European-based patient groups and clinicians managing families affected by multiple endocrine neoplasia (MEN) disorders. An online, multi-language patient survey regarding Quality of Care was developed and distributed by EMENA via its patient group and health professional members and on a variety of social media channels, including twitter and Facebook. A total of 289 responses were analysed. A single MEN4 response was excluded for lack of comparable responses and 4 duplicated or incorrect disease responses were excluded resulting in a total of 284 responses as detailed below.

RESULTS



A good response was seen from the UK, Italy, Germany and The Netherlands. Other countries represented are Belgium (n=7), Croatia, Denmark, Estonia, Finland, Poland, Portugal and Switzerland (n=1), Greece and Sweden (n=2), Ireland (n=3), Norway and Spain (n=5). Disease and gender split were as expected with MEN1 and female patients well represented.



Over half of all respondents were aged between 41-60 years (52.85%) and were diagnosed with a positive genetic mutation after presenting with MEN-related tumours (67.8%).

Median time to diagnosis from presentation of first symptom was 2 years and the median number of doctors visited prior to diagnosis was 2. Average (median) travelling time one-way for MEN care was 1 hour.

Endocrinologists in specialist reference centres were commonly in charge of the care of MEN patients in both the UK and throughout Europe. (See P072 for Patient Perception of *Quality of Care*). Around 20% of respondents were unsure if an MDT was involved in their care. Specialist endocrine nurses were identified more readily by patients in the UK, although there remains a substantial gap in provision or awareness of the role both in the UK and across Europe.



CONCLUSIONS

The majority of MEN patients who completed our questionnaire are cared for by an endocrinologist, based in a specialist reference centre or centre of expertise. Despite this, access to a Specialist Endocrine Nurse was reported as more common in the UK than in mainland Europe, although no one disease group had this advantage over another. Lobbying for increased specialist nursing may be a useful focus for patient advocacy groups outside of the UK. There were no other significant differences between the care provided to patients in the UK and the rest of Europe. Nevertheless, further work is required Europe-wide to educate patients about expert multi-disciplinary team working and the importance of these teams in the care and management of MEN patients.

