

P072. Patient Perception of Quality of Care for Multiple Endocrine Neoplasia Disorders In the United Kingdom Compared to Other Countries within Europe

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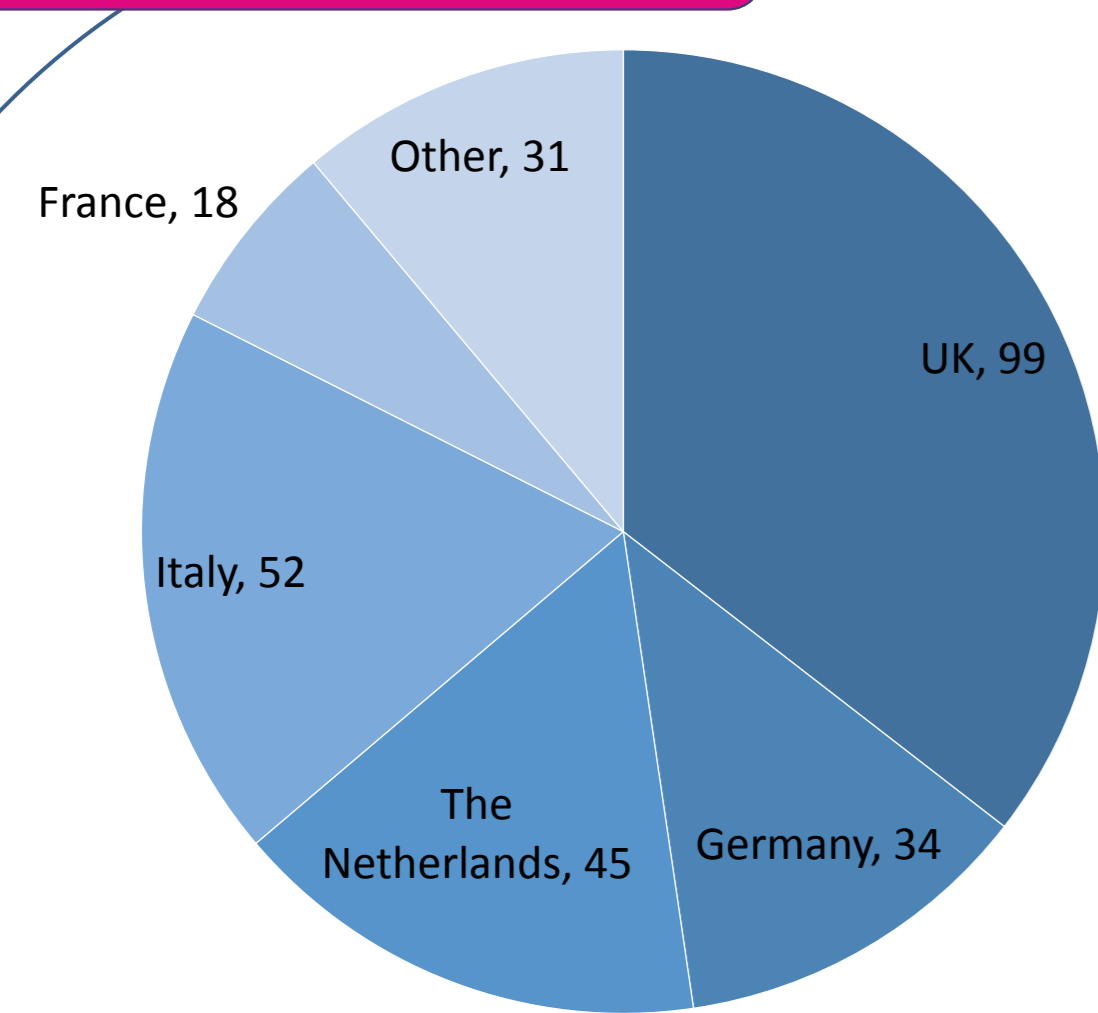
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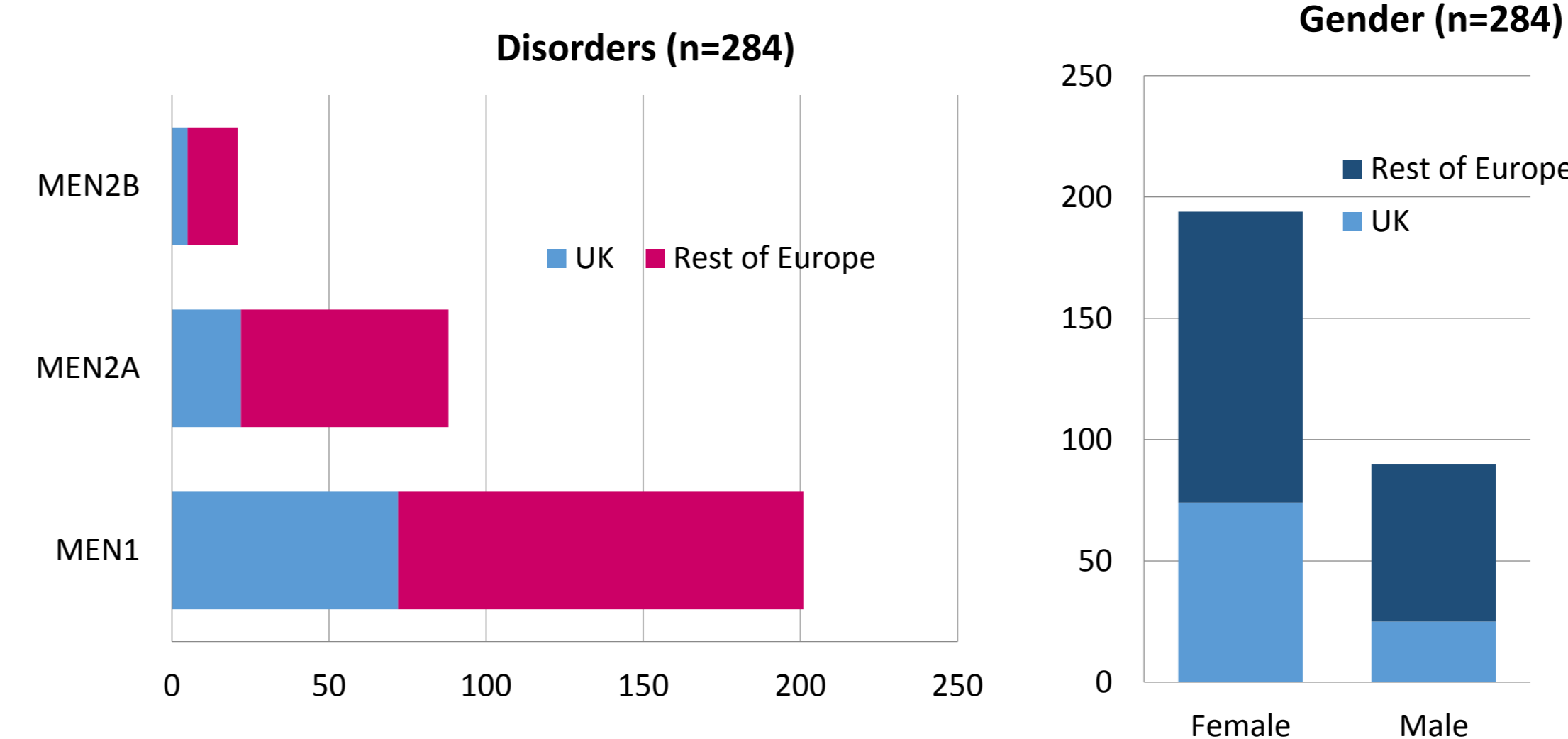
METHOD

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



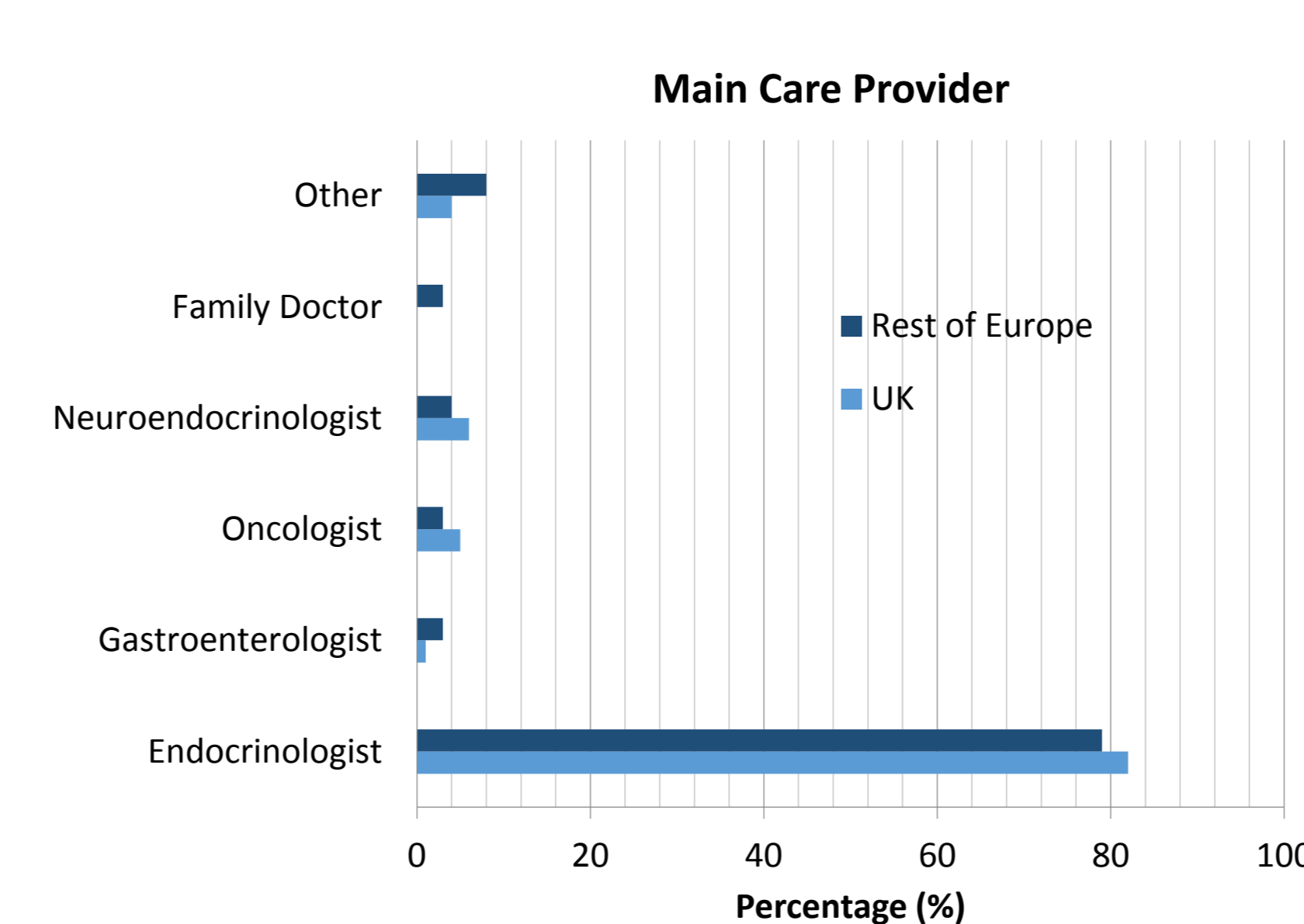
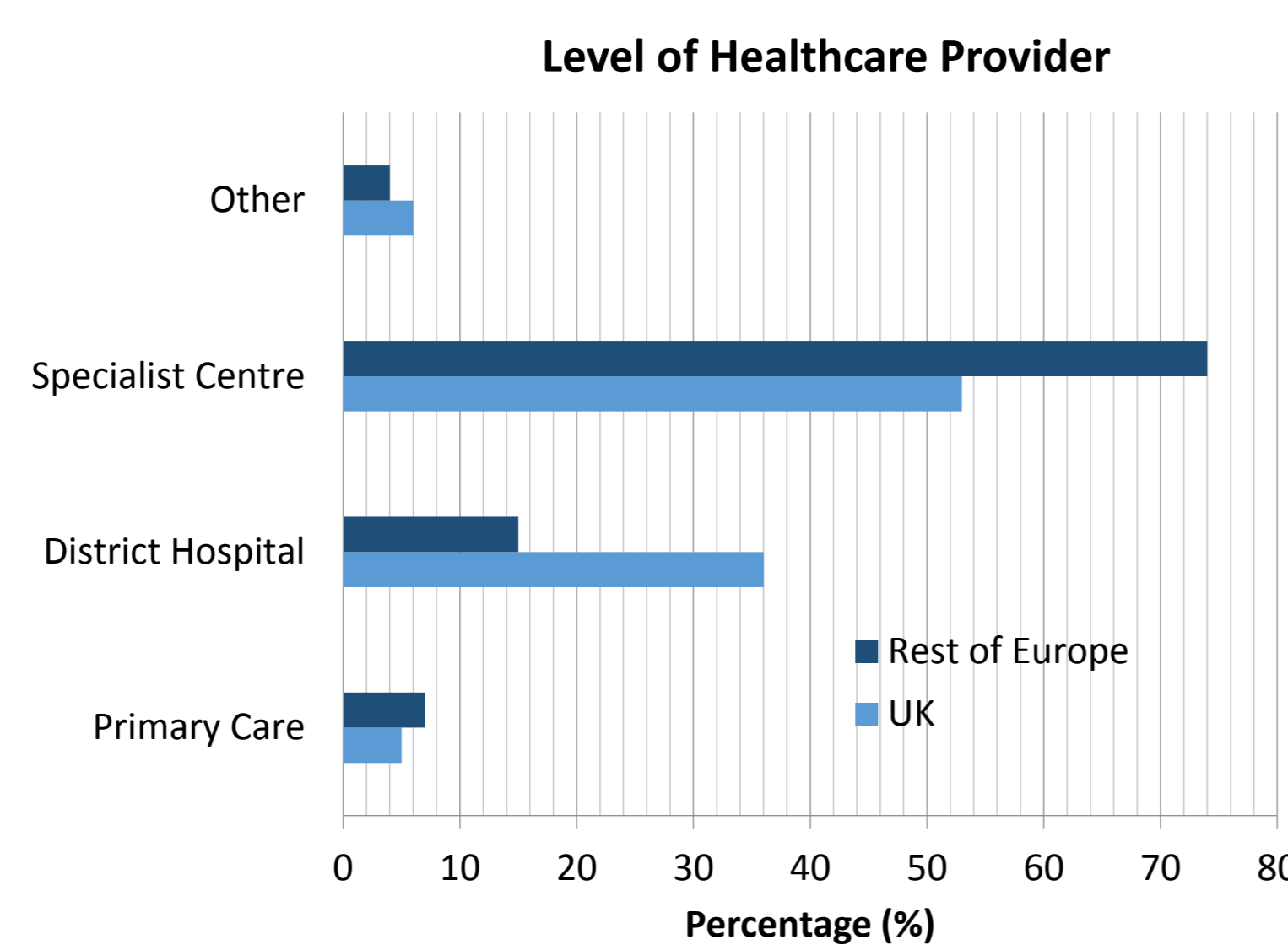
A good response was seen from the UK, Italy, Germany and The Netherlands. Other countries represented are Belgium (n=7), Croatia, Denmark, Estonia, Finland, Poland, Portugal and Switzerland (n=1), Greece and Sweden (n=2), Ireland (n=3), Norway and Spain (n=5). Disease and gender split were as expected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



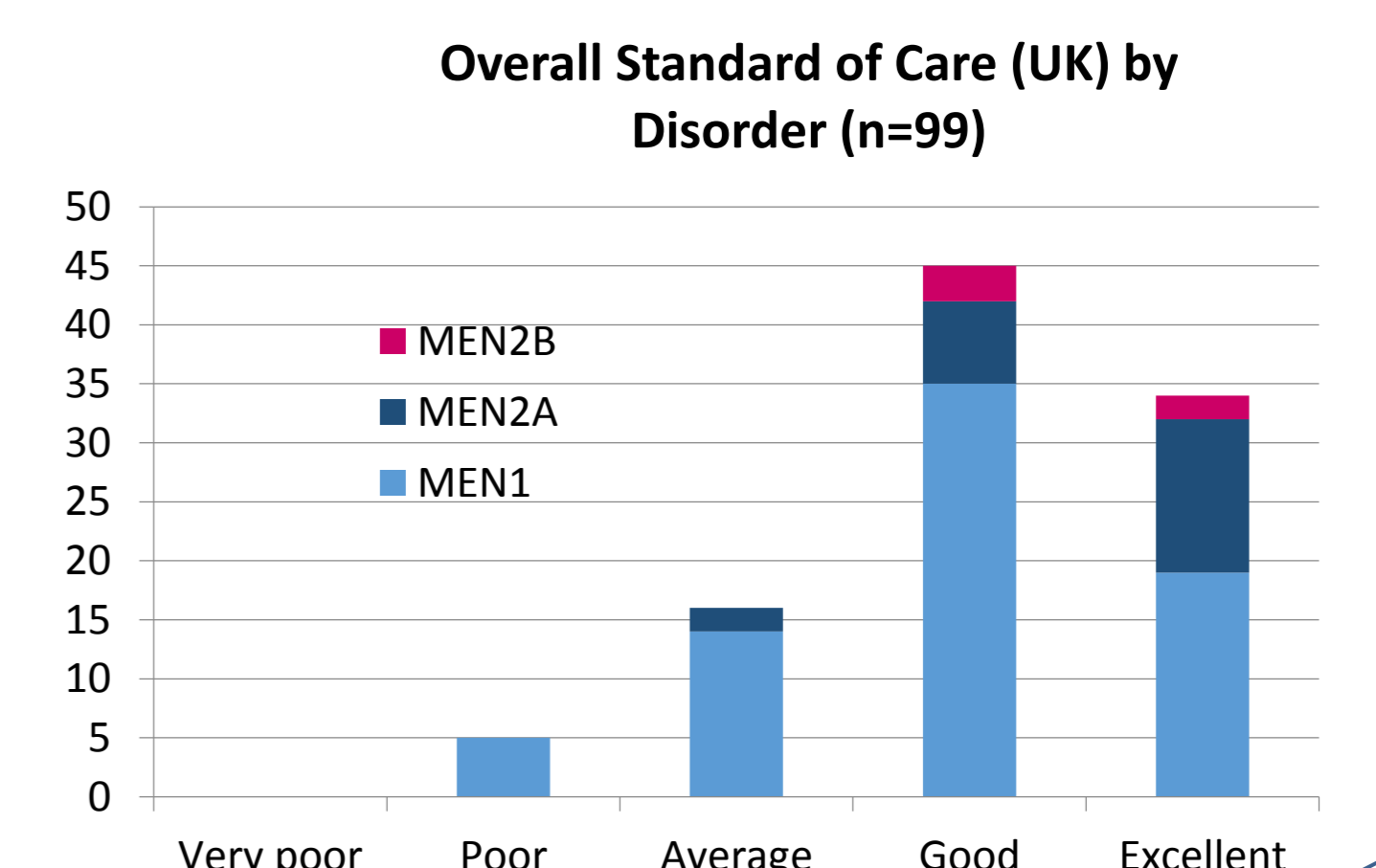
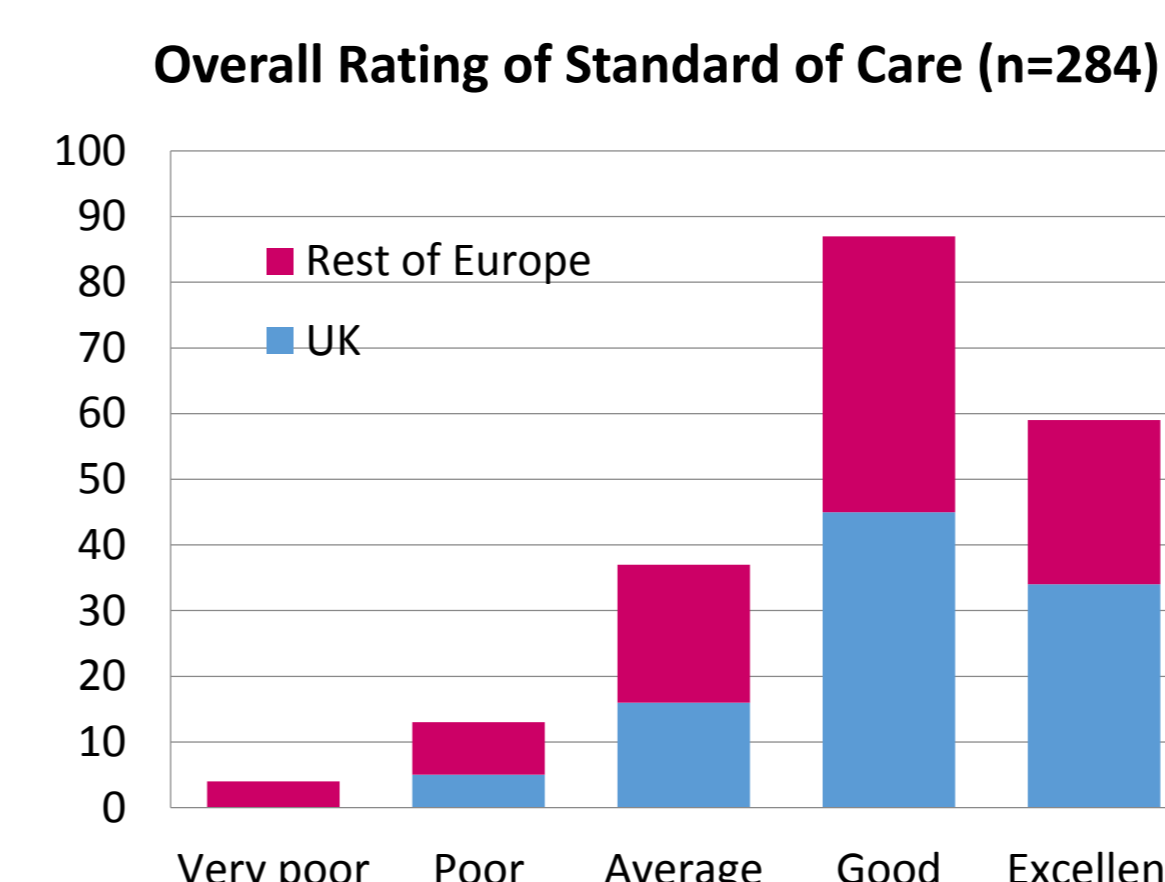
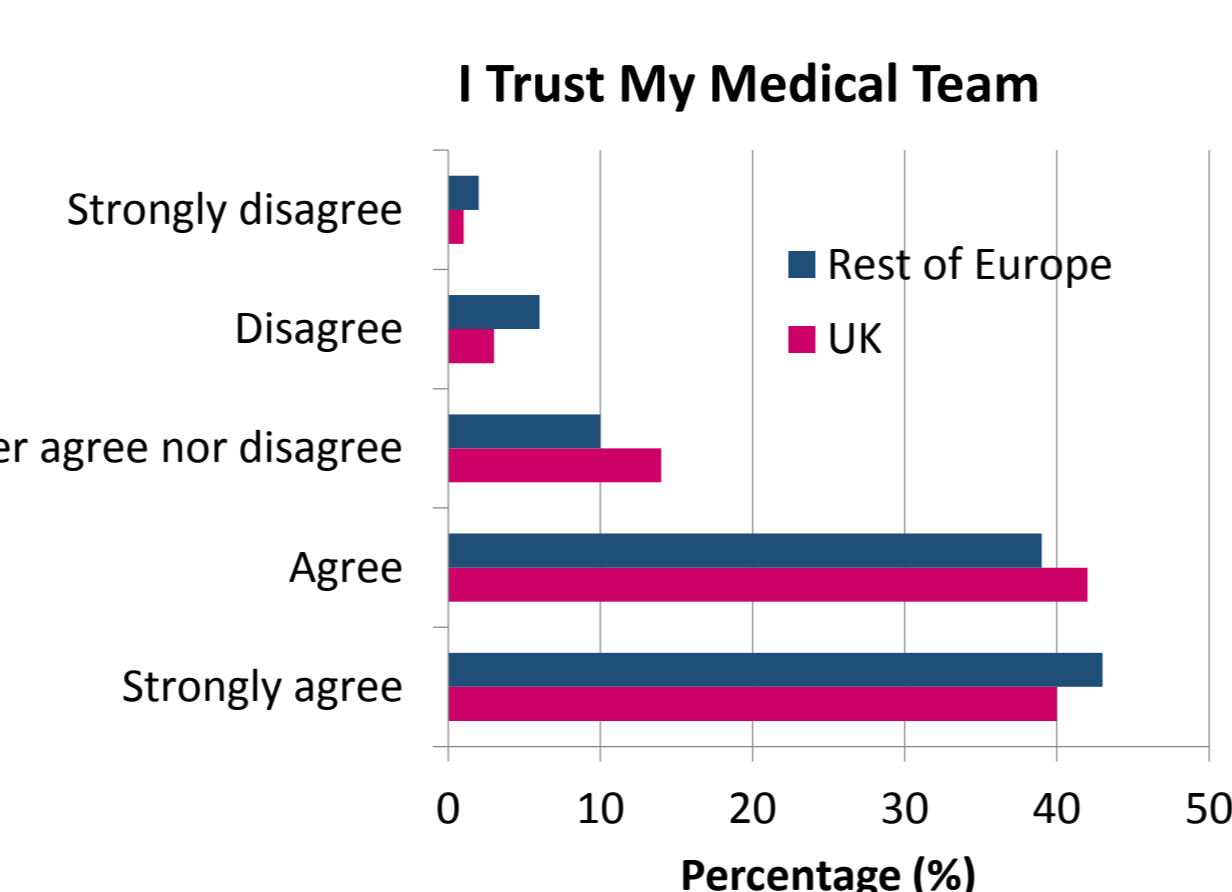
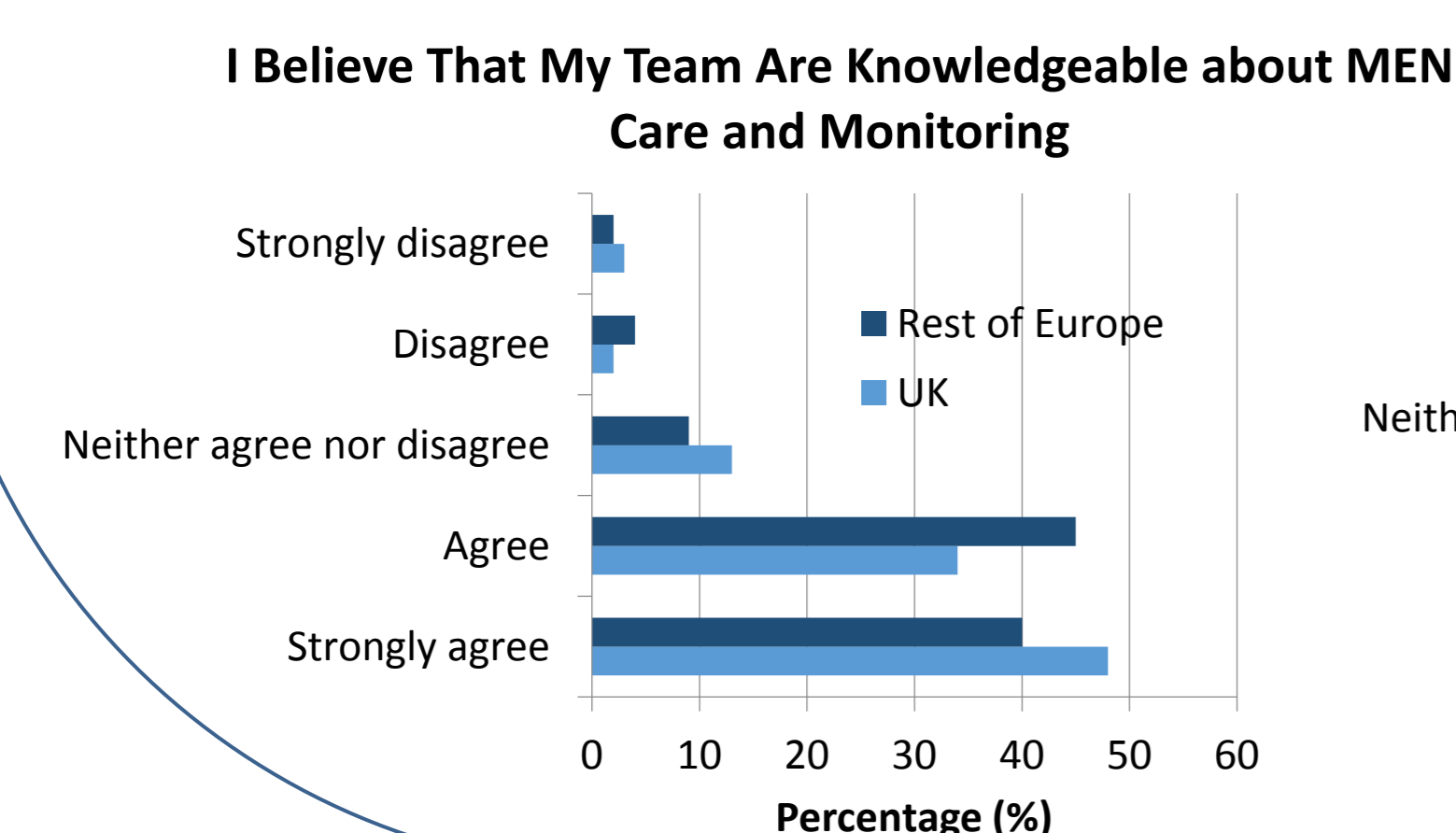
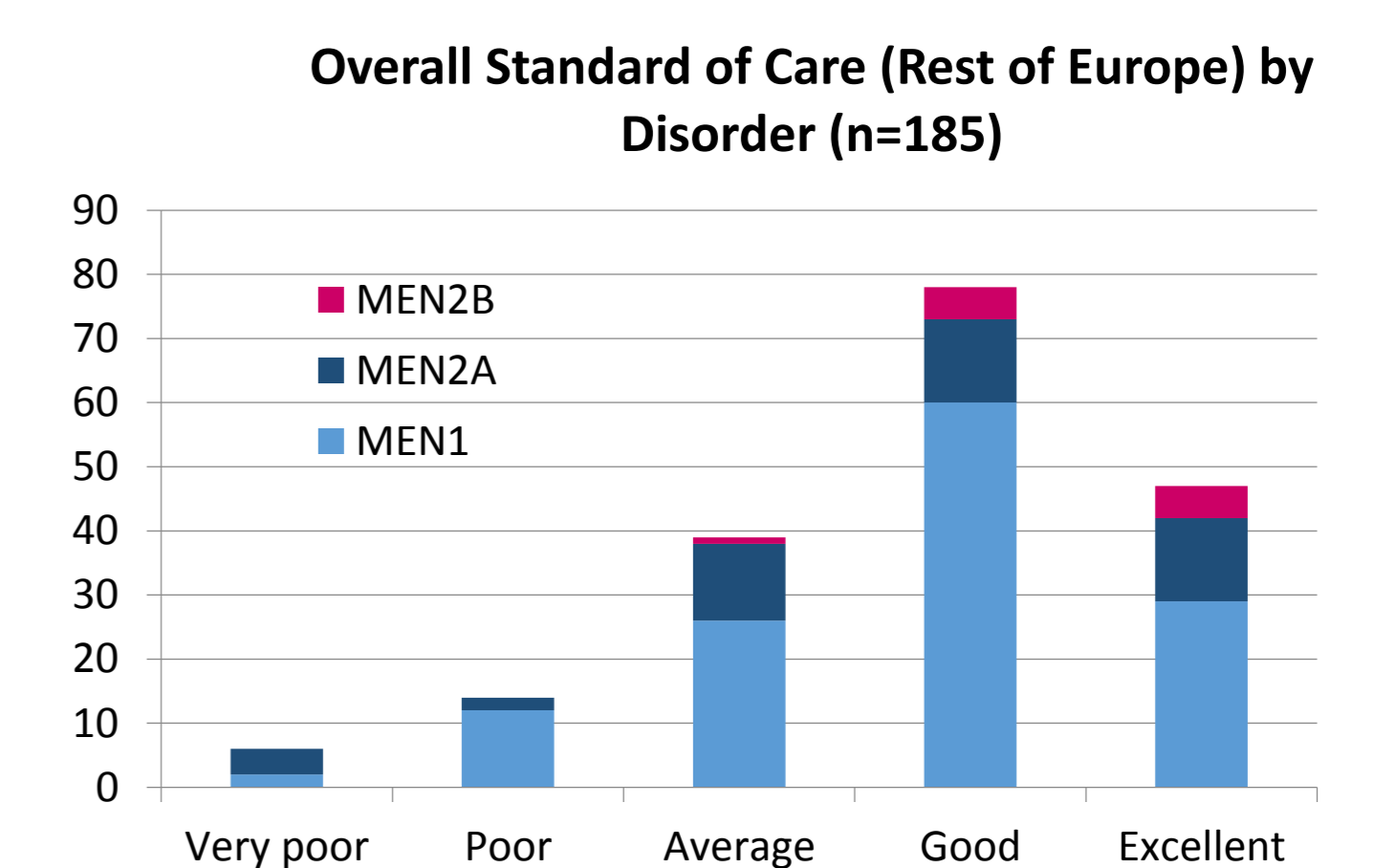
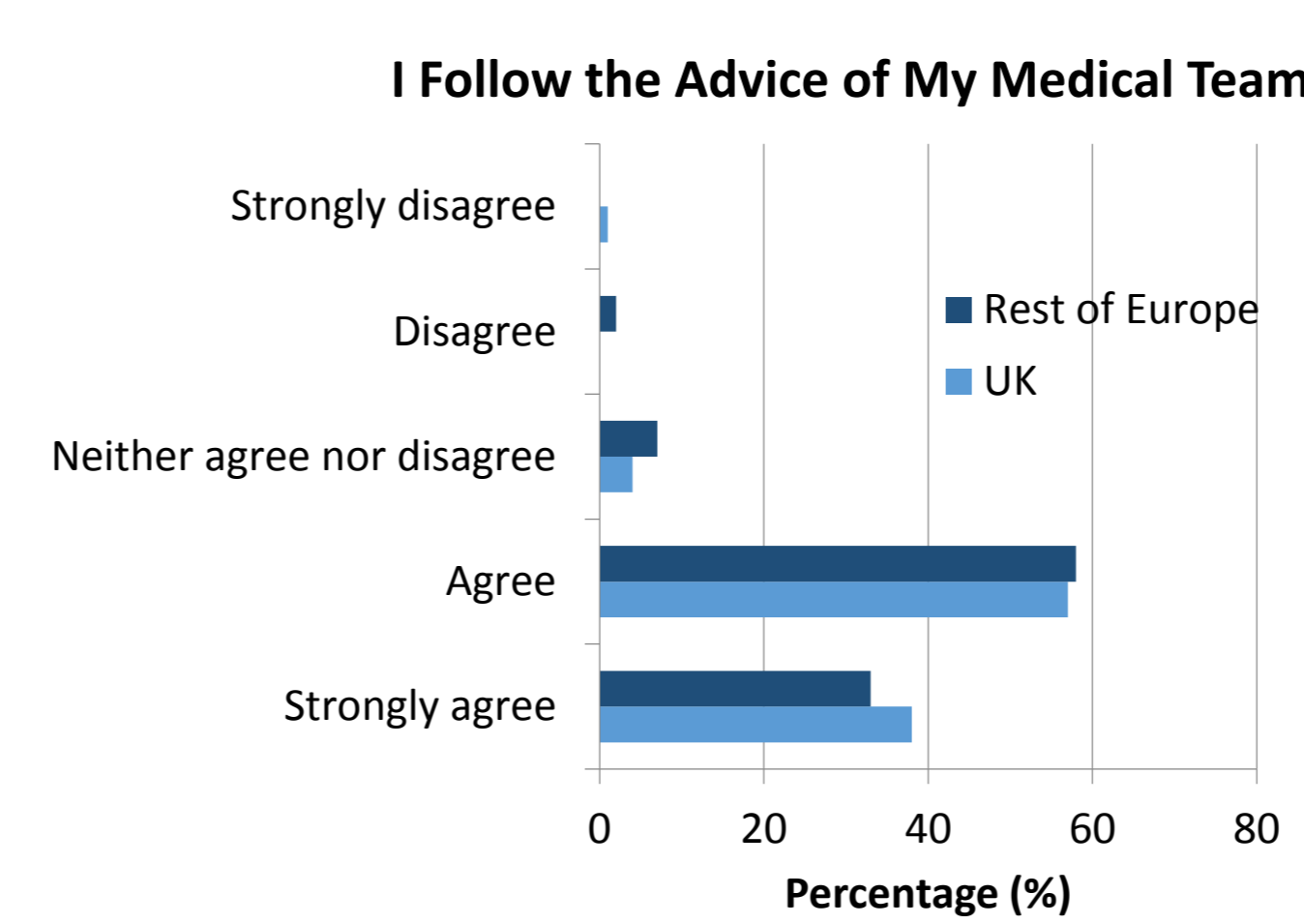
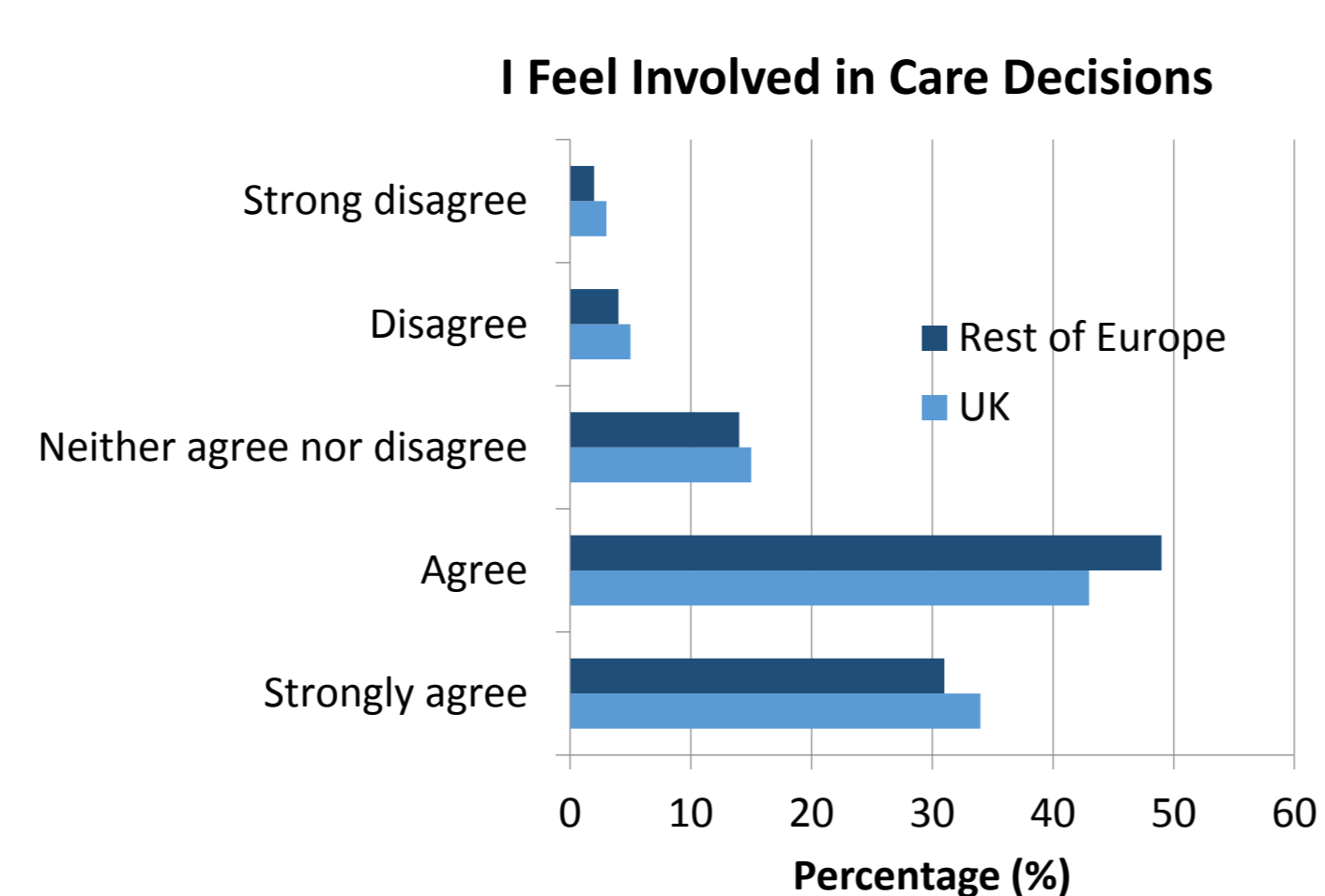
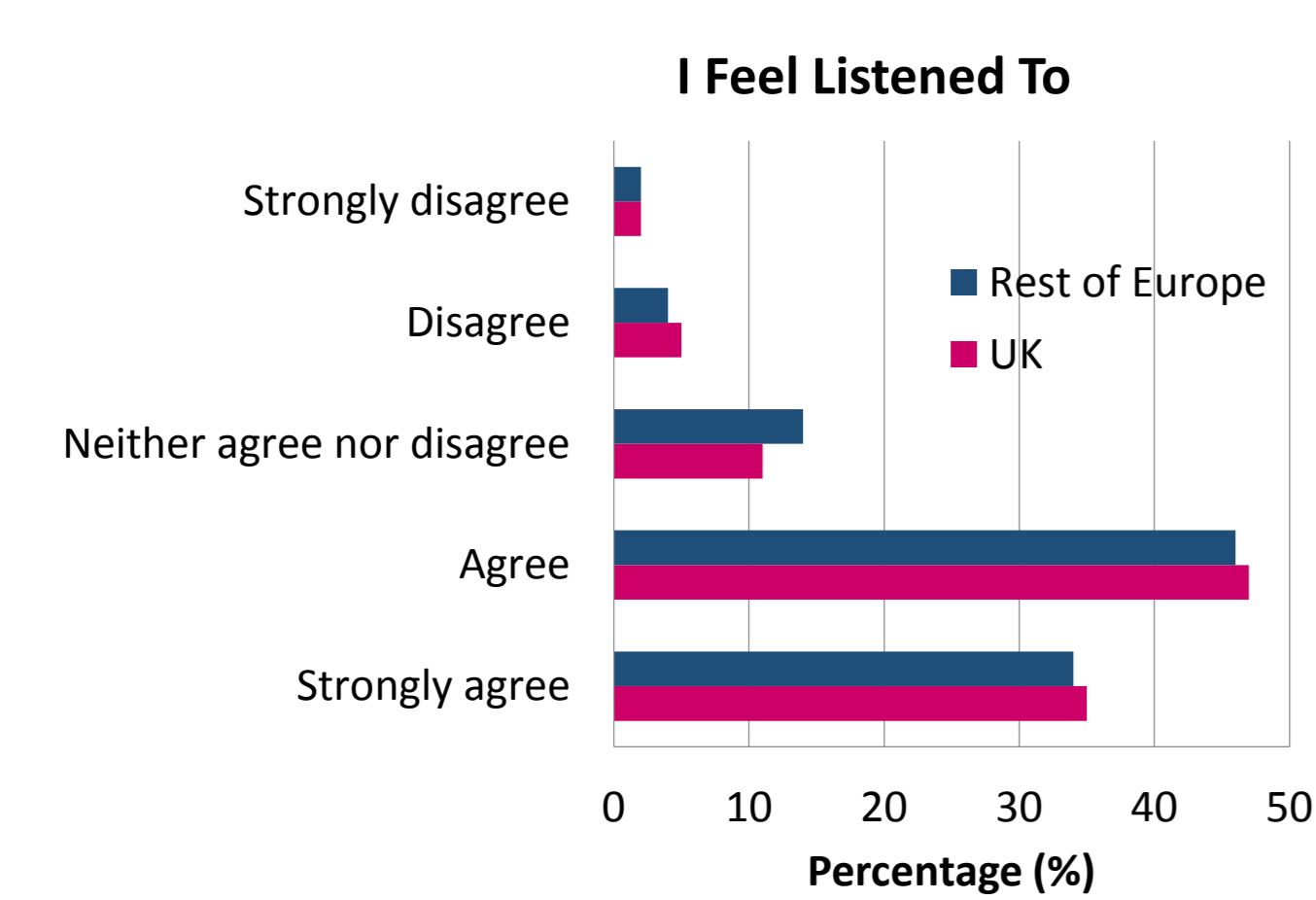
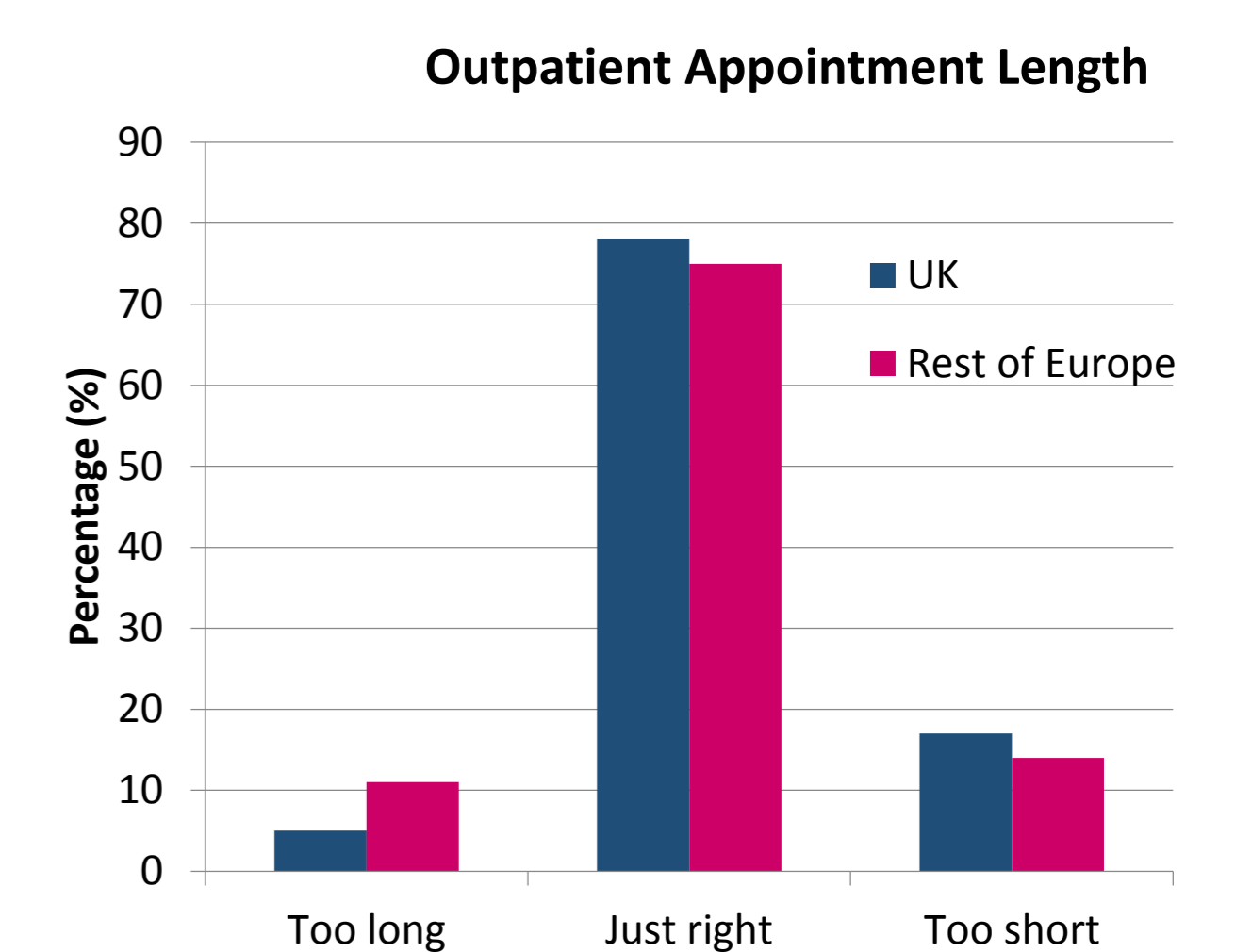
Over half of all respondents were aged between 41-60 years (52.85%) and were diagnosed with a positive genetic mutation after presenting with MEN-related tumours (67.8%).

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 P306 for more information on the differences and similarities in the provision of care in MEN throughout Europe).



We asked patients to rate aspects of their interactions with the medical team in charge of their MEN care. There were no significant differences; however, the generally strong scores were not reflected in the overall rating of care.



CONCLUSIONS

Overall, these results indicate that, in the main, patients believe that endocrinologists in specialist centres are providing high quality care for patients with multiple endocrine neoplasia disorders both in the UK and elsewhere in Europe. Patients commonly feel listened to and involved in care decisions, and consider their team knowledgeable about the care and management of MEN patients. The majority trust and follow the advice of their specialist. However; these ratings are not as convincingly reflected in overall ratings of standard of care, with the majority of patients rating their overall care as 'Good'. Further analysis shows that the patients who most highly rate their care are MEN2A patients in the UK. A limitation of this study is the high proportion of patient advocacy group members who responded and who may already be more engaged in and therefore happier with their healthcare. However, these results should be viewed as encouraging feedback for endocrinologists who care for MEN patients, and may also be used as evidence to help encourage patients to request referrals to centres of expertise for MEN.

