Patients’ view on the unmet need in endocrine medical research

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INTRODUCTION
• The mission of Endo-ERN is to reduce inequalities in care for patients with rare endocrine conditions
• Patient representatives are involved in steering committees
• Work package ‘Research & Science’ aims to capture unmet needs of patients

METHODS
• Survey in 22 languages on unmet needs in research
• Distributed via patient advocacy groups, reference centres of Endo-ERN, and Orphanet newsletter
• Patients scored priorities on a 3 point scale (1, most; 3, least important)
• Results were analyzed comparing gender and disease groups (MTGs)

RESULTS
• 1387 individual responses from 27 European countries
• Eastern Europe underrepresented
• Most interest in research concerning ability to work and participate in social life and tiredness
• Interest in research on tiredness differed between MTGs

CONCLUSIONS
• We report on a large sample of European patients with a rare endocrine disease
• Patients with rare endocrine diseases experience unmet needs in research
• These needs differ between disease groups

FUTURE
• Answers to open questions will be analyzed for more detailed assessment of patients’ needs
• Discussion on results within MTGs

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