

Meeting Unmet Needs through Registries- an example from German MEN patients

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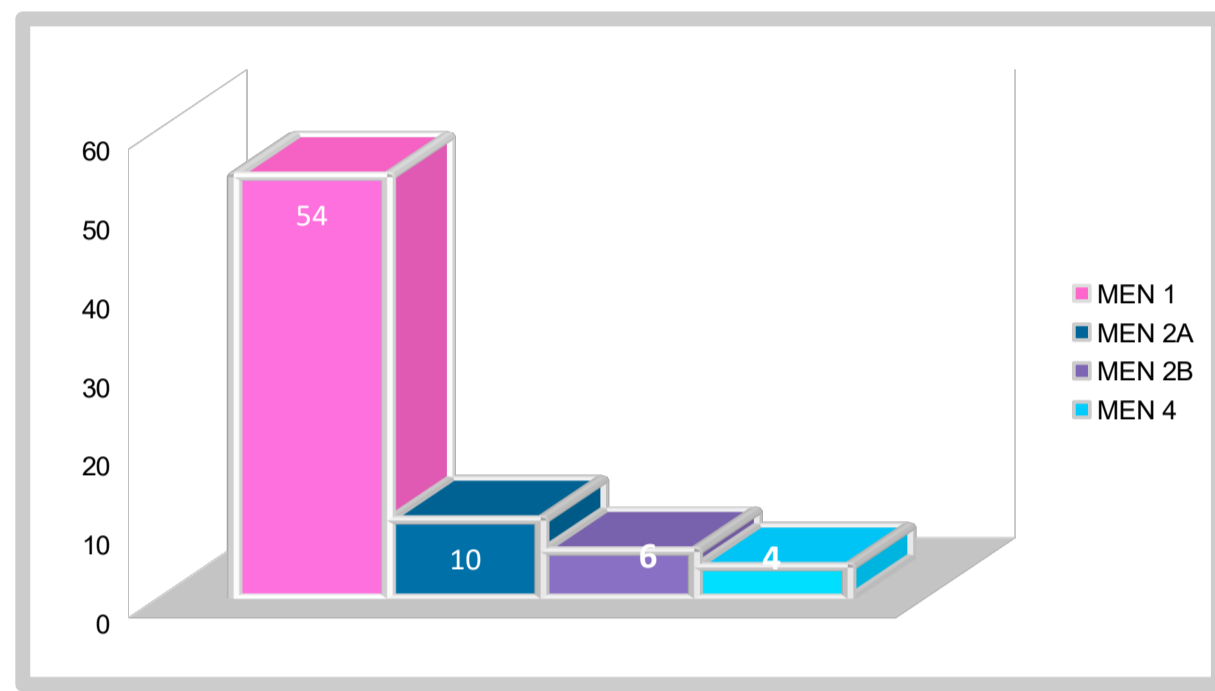
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Methods

The German **Network for Pituitary and Adrenal Disorders (Netzwerk Hypophysen – und Nebennierenerkrankungen e.V.)** conducted a nationwide survey on unmet needs of patients with multiple endocrine neoplasia (MEN) in Germany. The study aimed to identify unmet needs in care and quality of life, as well as potential areas of improvement. The survey was based on a questionnaire developed by the **European MEN Alliance e.V. (EMENA)** an alliance of European-based patient groups and clinicians managing families affected by multiple endocrine neoplasia (MEN) disorders. The survey was distributed by the German Patients' advocacy group using the European Commission's EU Survey platform among group members, physicians, and social media. A total of 73 responses were analysed.

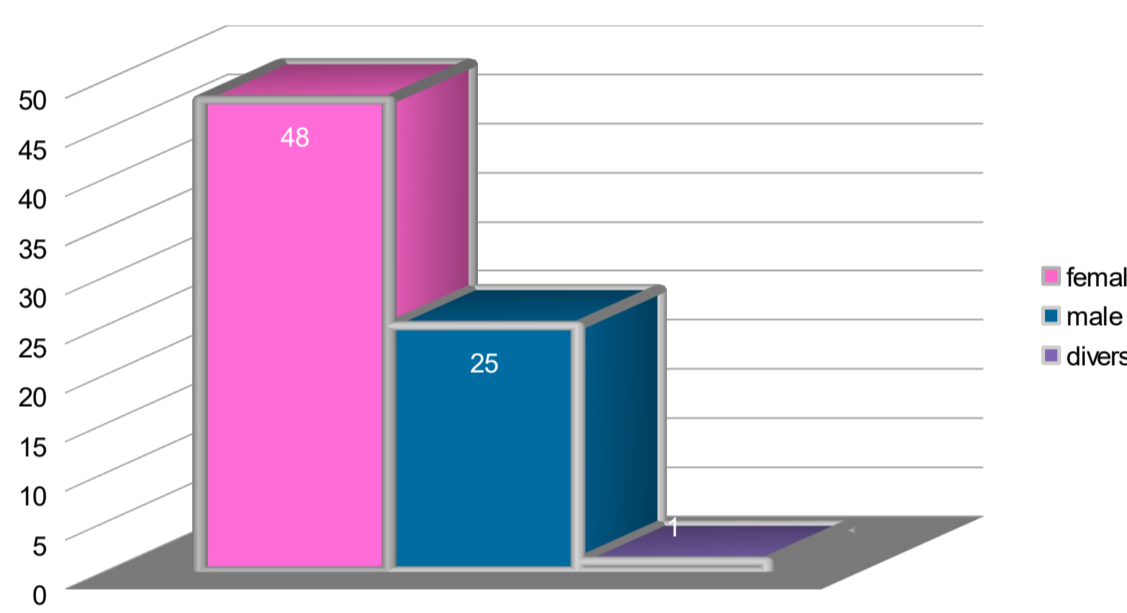
Results

Disorder type



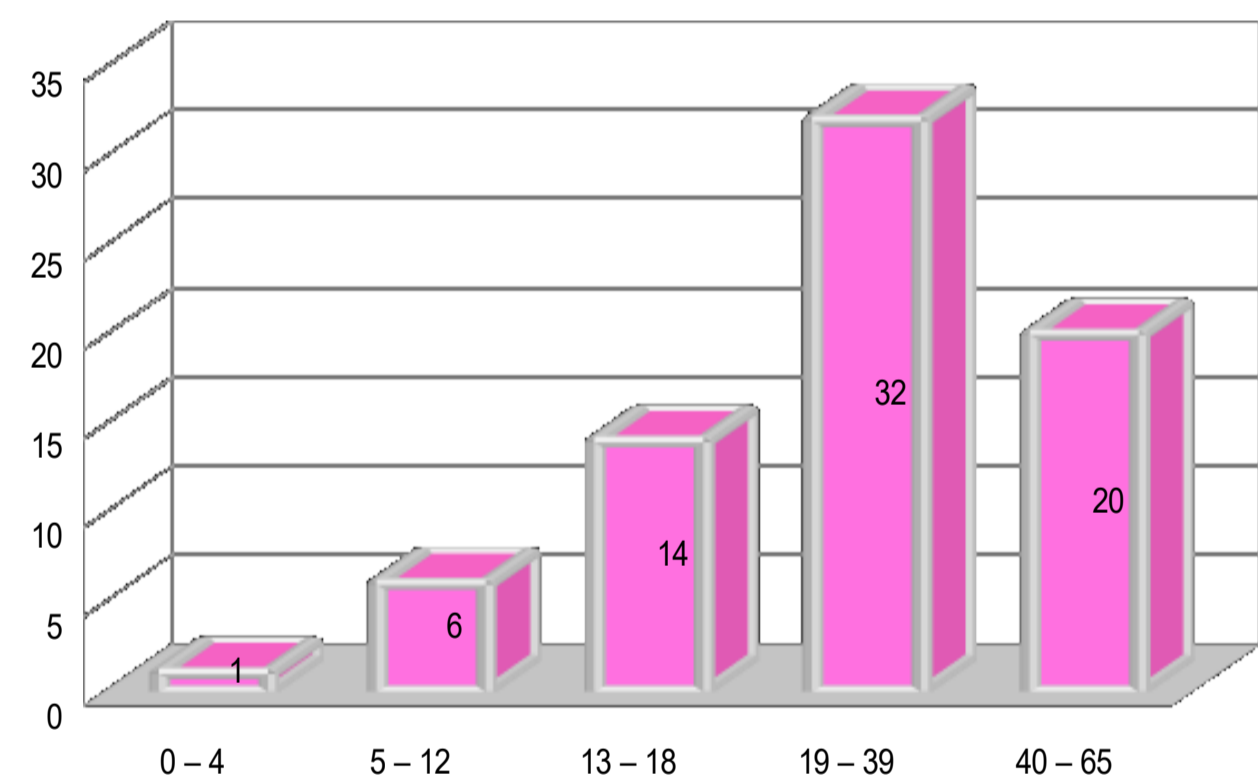
54 cases of MEN1,
10 cases of MEN 2A,
6 cases of MEN 2B and
4 cases of MEN 4 were included.

Gender



65 % of the respondents were female.

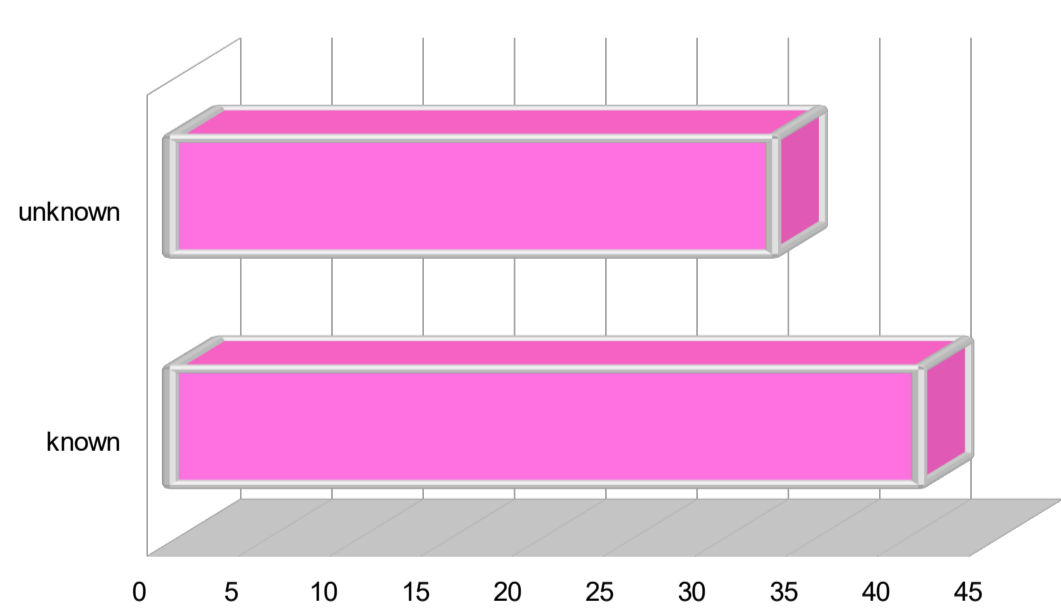
More than half of all respondents were aged between 40-60 years (62.1%) and nearly all were diagnosed with a positive genetic mutation after presenting with MEN-related tumours (90.8%).



At what age was the diagnosis made ?

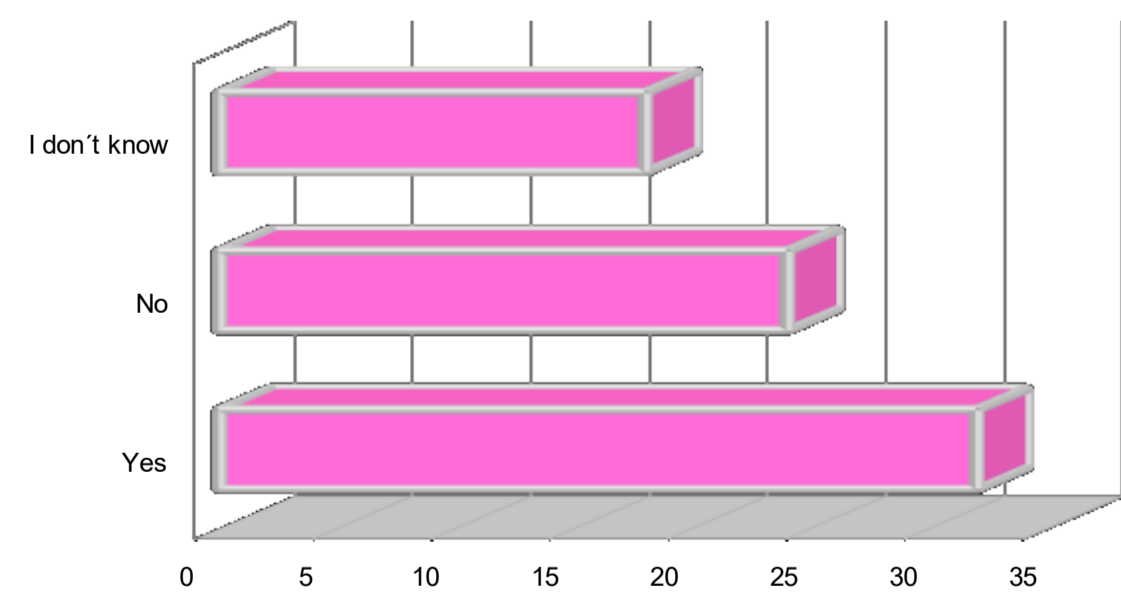
Mostly the diagnosis was made in the age from 19 to 39.

Treatment in a Center of Excellence and Involvement of a multidisciplinary team (MDT)

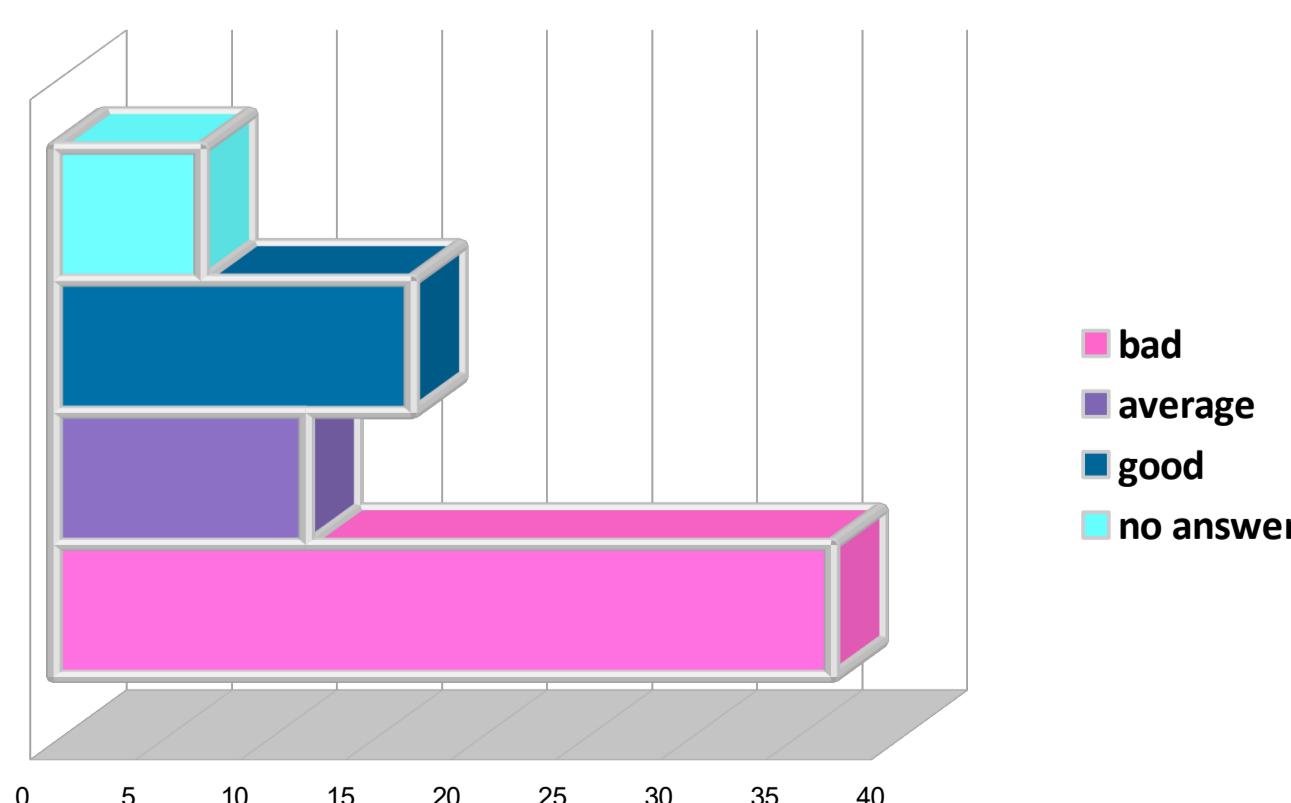


Do you know a Center of Expertise ?

Around 20% of the respondents were unsure if an MDT was involved in their care.



Is a multidisciplinary team involved in your MEN care ?

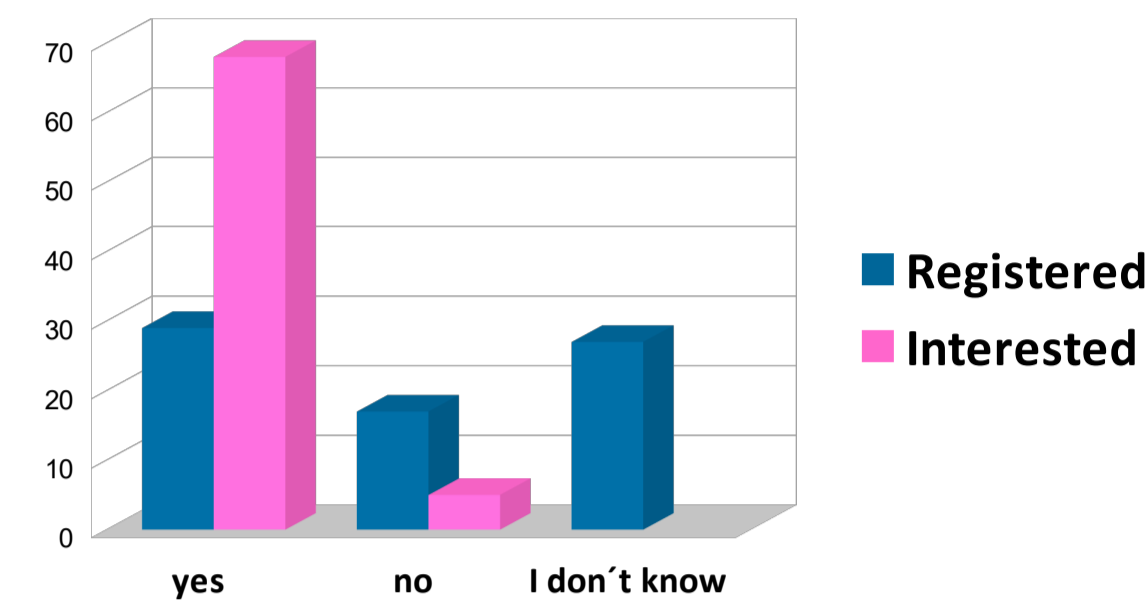


About 40 % rate the communication among the specialists and the General practitioner as bad

Are you registered in a MEN Research database ?

29 (39,1 %) respondents are registered in a MEN Research database. Only five of the respondents aren't interested to be involved in a database.

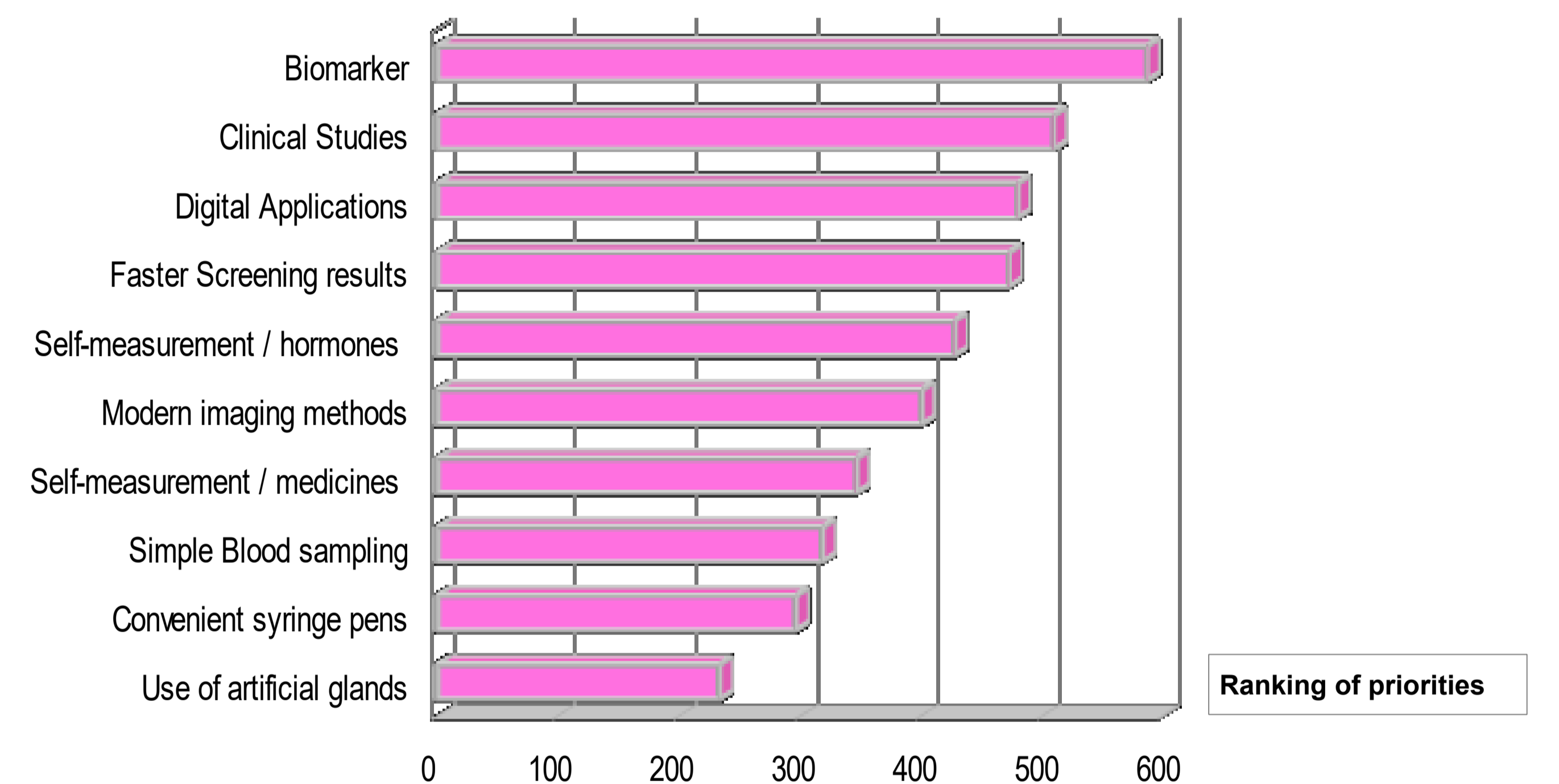
Most of the respondents are interested to spend their data to a registry but are not involved yet.



Expectations for the Research database

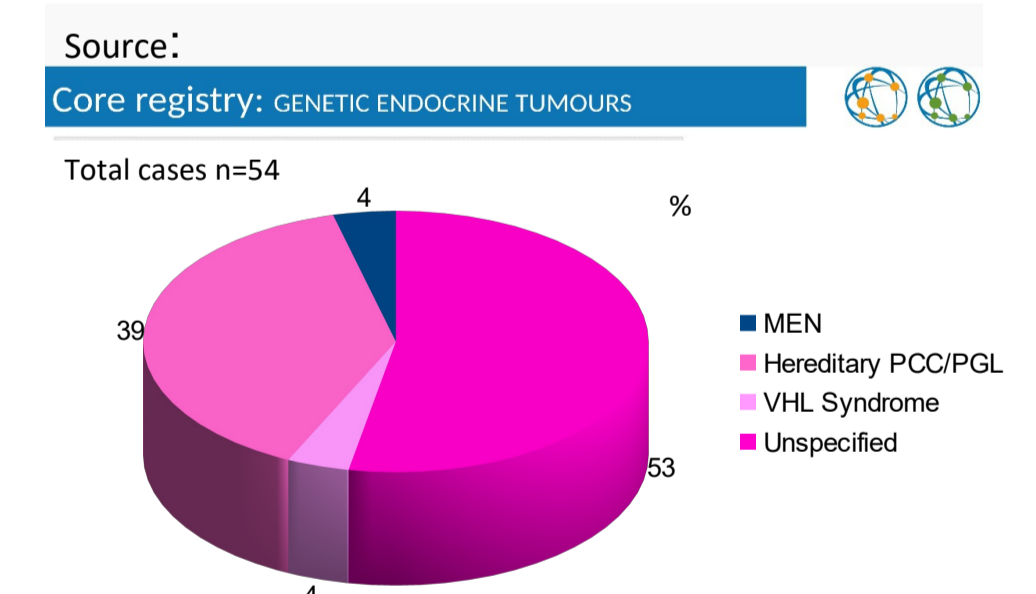
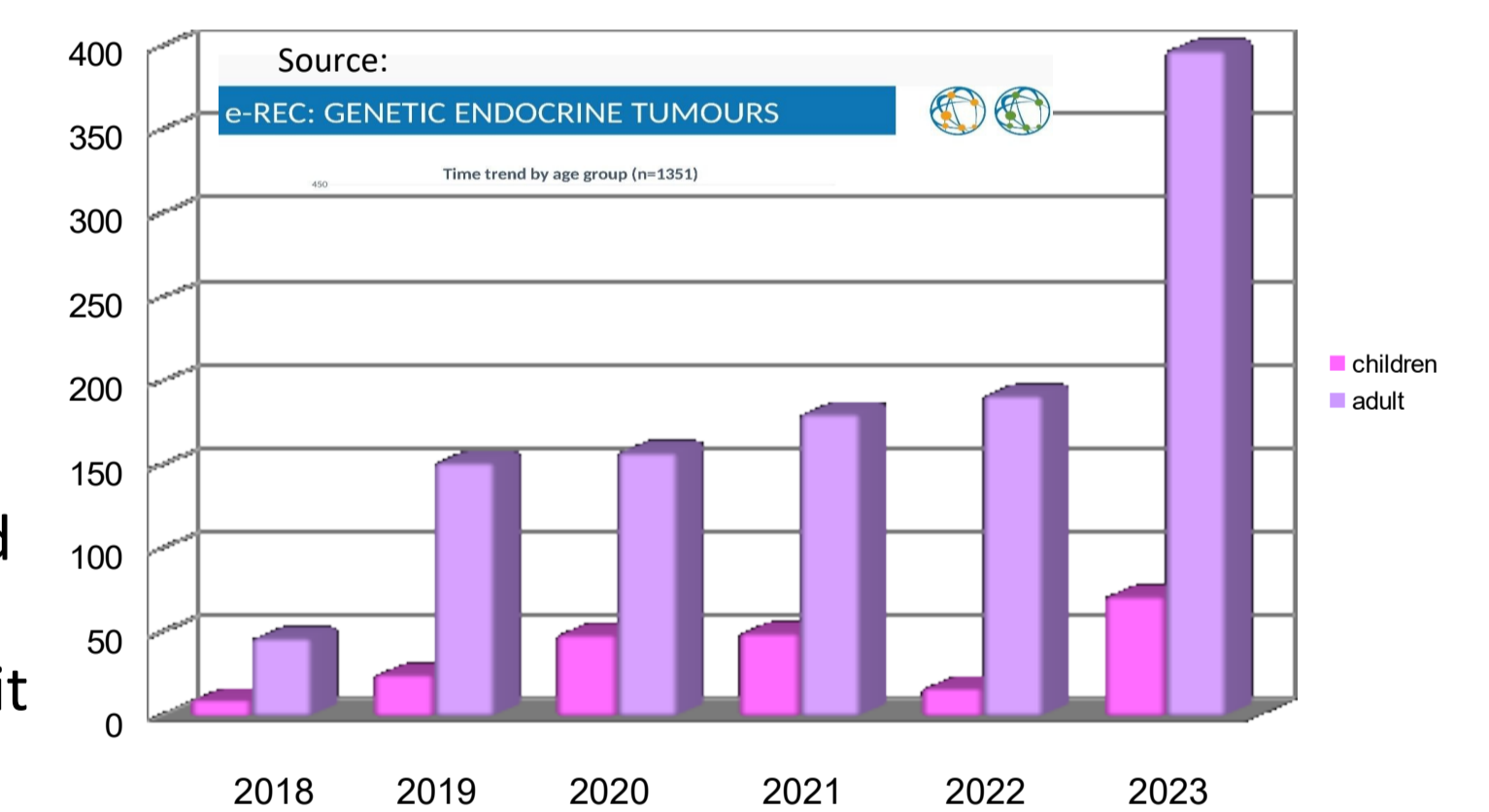
Biomarkers for detecting and predicting possible tumour recurrences are a top priority when it comes to **unmet needs** in the treatment of MEN patients. Additionally, patients and their families desire **faster screening results** and further **research** into the disease.

Modern **imaging methods** and improvements in **self-measurement** of hormones and medicines are also on their wish lists.



Ranking of priorities

Registries are high valued throughout Europe. The EU Commission spend a big amount on the establishment through the ERNs, the European Medicine Agency and all funding possibilities. **EuRRECCa** is established and works - now it is time that the project is better known among the clinicians, the patients and the research community to be used for the benefit of patients. Maybe the only way to increase participation is to offer an attractive remuneration to the physicians if patients' s data are entered.



Conclusions

Further research projects in the field of MEN are necessary to achieve the desired improvements for previously unmet needs.

The MEN patients named several unmet needs: The ranking was led by biomarkers to predict new tumours or recurrences, second by more clinical trials, followed by digital tools for quick screening results, faster tests and scans, and self-monitoring of hormones in the blood. All these improvements can only be achieved if sufficient data (and in future bio banks) are available.

It is noteworthy that 60% of these patients are not registered in any database. Additionally, approximately 80% of all respondents are interested in registries. **The majority of MEN patients are willing to make their data available for research, but they are not proactively given this opportunity, at least in Germany as the survey shows.**

So one of the goals of patients' advocacy groups to **improve the utilisation of registries** is the rising of awareness and simplifying possibilities to include patients in databases.

Many MEN patients are interested to provide their data, but the way to do it, should be simplified. Therefore, it is the responsibility of patients' s advocacy groups for all Rare diseases to draw attention to these opportunities, open doors and argue to make it easy and convenient for all stakeholders – physicians, patients, researchers to take advantage of the registries .

Only with the help of registries we 'll address the unmet needs mentioned by MEN patients in the long run.