

01. Introduction

In the field of health technology assessment (HTA), the inclusion of patients' perspectives offers a vital opportunity to capture unique insights into patient experiences, unmet needs, and their advocacy for access to innovative treatments. Integrating the patients voice in HTA appraisals upholds the ethical principles of respect for autonomy and justice, ensuring patients' rights and interests are actively considered in health-related decision-making processes. In Ireland, the National Centre for Pharmacoeconomics (NCPE) facilitates this by calling for submissions from patient organisations (POs) following a full HTA submission by an applicant. These submissions enable POs to effectively communicate the lived experiences of patients, which can play a critical role in influencing the outcome of HTA evaluations.

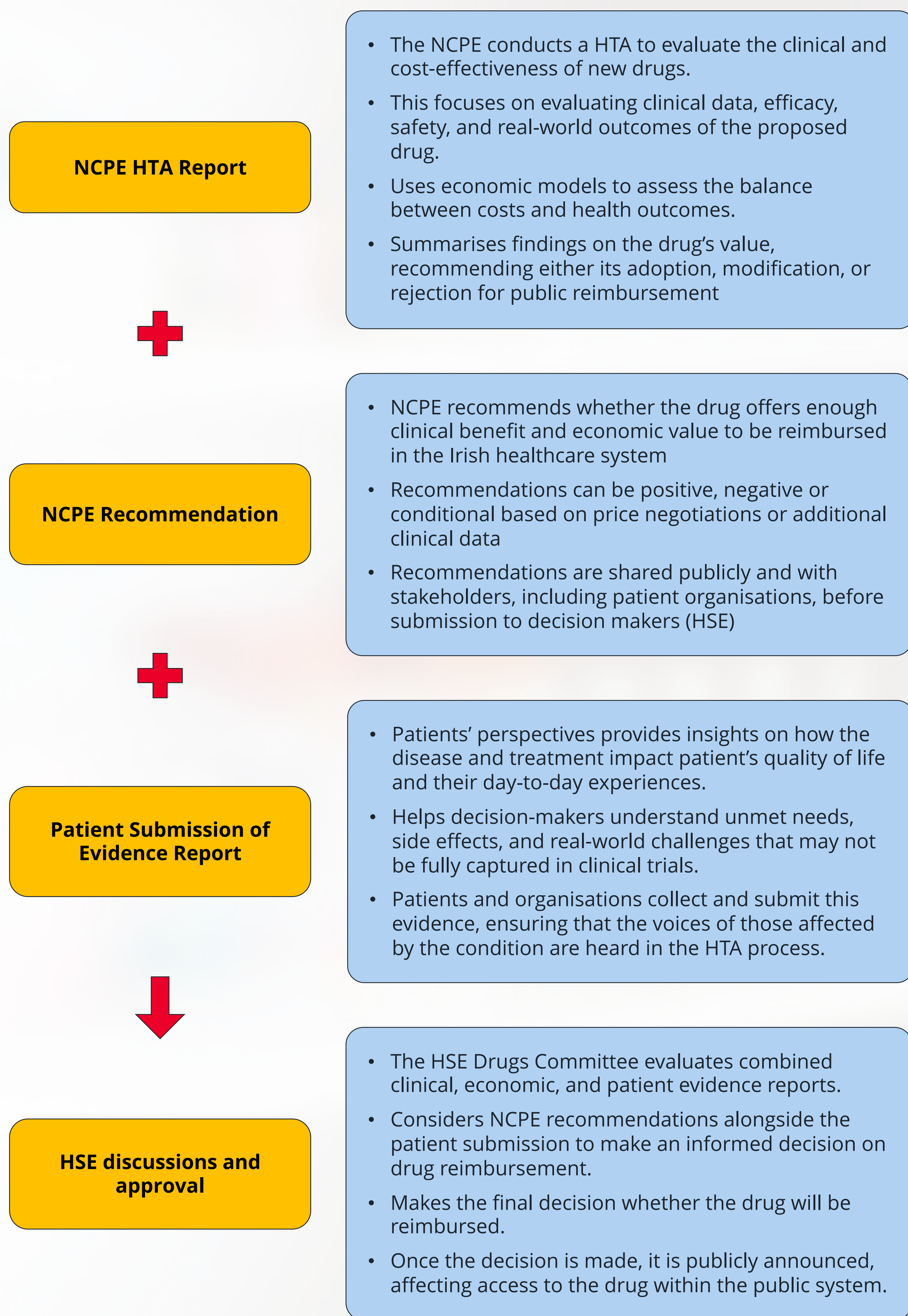
Research Aims

- This study seeks to identify the annual breakdown of PO submissions from 2020 to 2024, categorising them into submissions of treatment for oncology and non-oncology indication. This allows us to understand the focus of patient organisations on cancer-related conditions versus other medical conditions over time.
- We aim to show the increased need for the patient voice to be heard throughout the HTA process and how this can have a valuable impact on patient outcomes

02. PO in HTA process

Understanding patients' experiences and perspectives is key part of the reimbursement process. Patients provide valuable insights into the advantages and disadvantages of currently available therapies, which may not be reflected in the literature or well understood by experts in HTA and decision-makers.

Additionally, patients play a crucial role in describing the burden of disease, helping decision-makers fully understand the unmet needs that novel therapies should address. Addressing the burden of disease requires a holistic understanding that extends beyond just medical or clinical outcomes. It involves recognising the economic, social, and emotional impacts of diseases on patients and society as a whole. By incorporating patient perspectives into decision-making, healthcare systems can better allocate resources and develop treatments that not only prolong life but also improve its quality. Addressing health inequalities and unmet needs is essential to reducing the overall burden of patients.



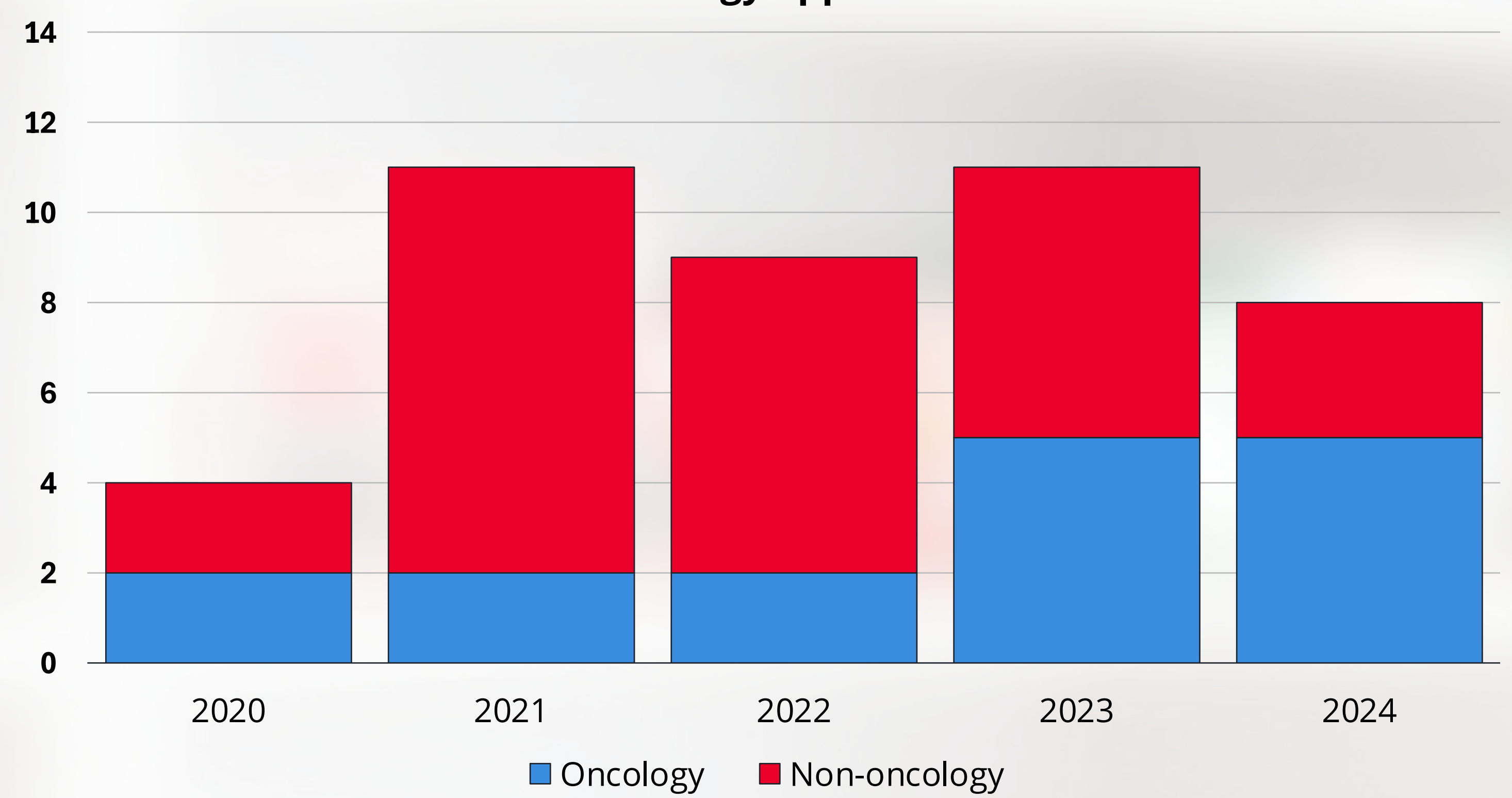
03. Methods

- A comprehensive analysis was undertaken to compile HTA evaluations completed between 2020 and 2024. This process involved gathering data for HTA bodies and integrating it into a unified database.
- Descriptive statistical methods were used to analyse the compiled data. The objective of using descriptive statistics was to quantify the overall number of PO submissions received throughout the assessment period.
- An updated assessment was completed up to August 2024 to include the most up to date research. This was to ensure that the most recent and relevant research was included. This involved integrating the latest HTA evaluations into the existing database to ensure the dataset was comprehensive and reflective of the current landscape.

04. Results

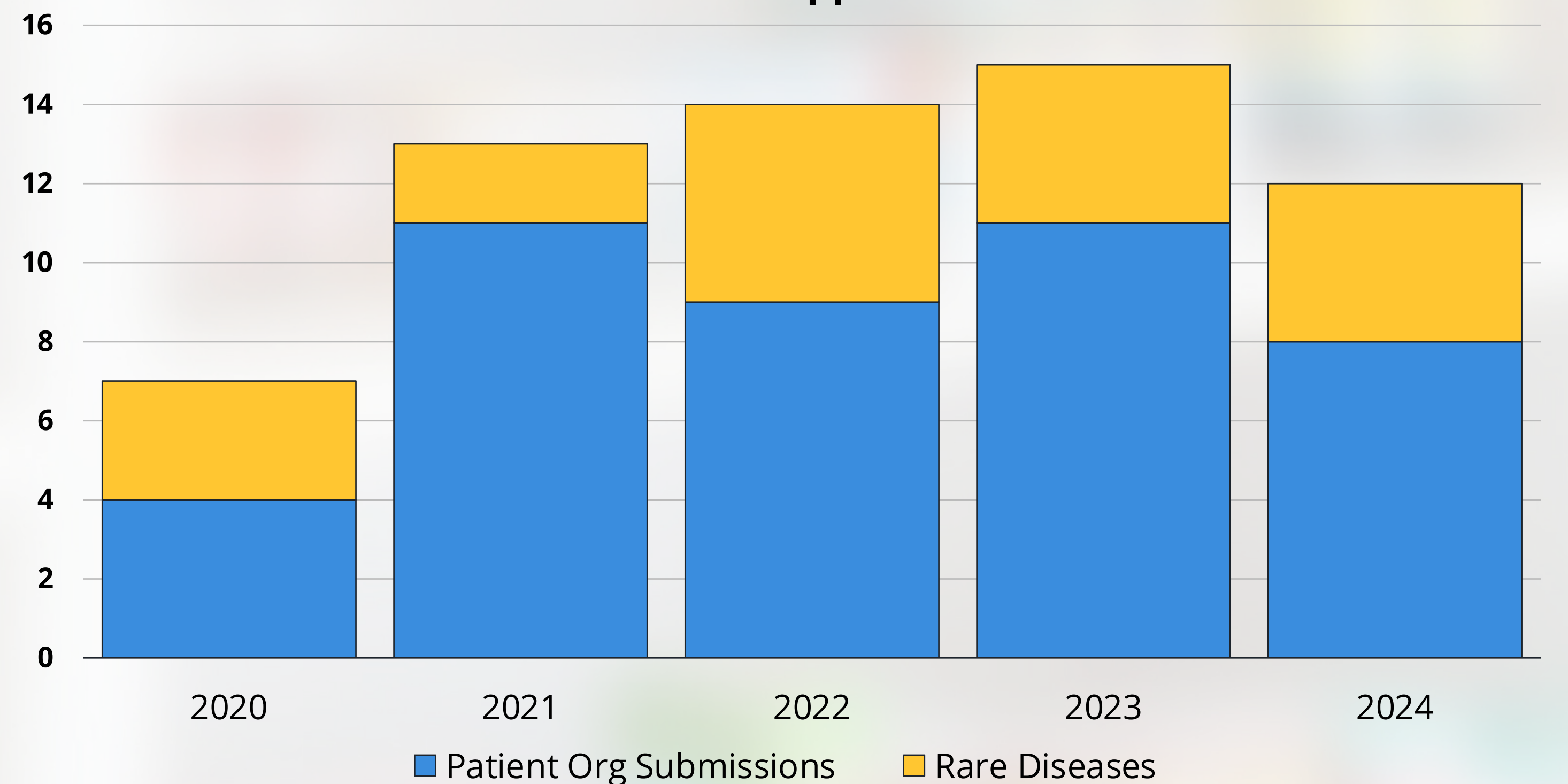
- Total Patient Organisation Submissions from 2020 have increased and remained consistent in subsequent years.
- Non-oncology PO submissions represent a significant portion of the total submissions, demonstrating the broad scope of conditions patient organisations are advocating for. Between 2020 and 2024, non-oncology submissions consistently outnumbered oncology submissions except for 2024. This suggests that while cancer care is crucial, patient organisations are also heavily focused on other therapeutic areas.

Patients organisation submissions in Oncology and Non-Oncology appraisals



- The analyses also covered submission for treatments for rare diseases which included PO submissions. From 2020 to 2024, submissions related to rare diseases varied slightly, with a high proportion of total PO submissions in 2020 and 2022. The consistent presence of rare disease advocacy reflects the unique challenges faced by patients with these conditions and highlights the importance of their representation in the HTA process.

Patient organisation submissions in Non-rare disease and Rare disease appraisals



05. Conclusions

- The data shows that the inclusion of patient organisation submissions in HTA assessments has grown steadily over the years, with a noticeable increase in submissions related to oncology from 2022 to 2024. This reflects the heightened awareness and advocacy around cancer treatments.
- PO submission for non-oncology conditions, however, continue to dominate in total submissions, highlighting the broad range of patient needs across many therapeutic areas.
- Submissions related to rare diseases have remained consistently important, reflecting the critical need for advocacy in conditions that may be underserved in traditional health care considerations.
- Ultimately, the active involvement of patient organisations in the HTA process not only strengthens the consideration of patient needs but also creates more equitable and patient-centred health policies that improve access to treatment for all patient groups.