

Assessing global access to treatments and care for people living with hyperinsulinism

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Objectives

Congenital Hyperinsulinism International conducted a survey of pediatric endocrinologists to assess global access to the key components of hyperinsulinism (HI) treatment and diagnostics.

Methods

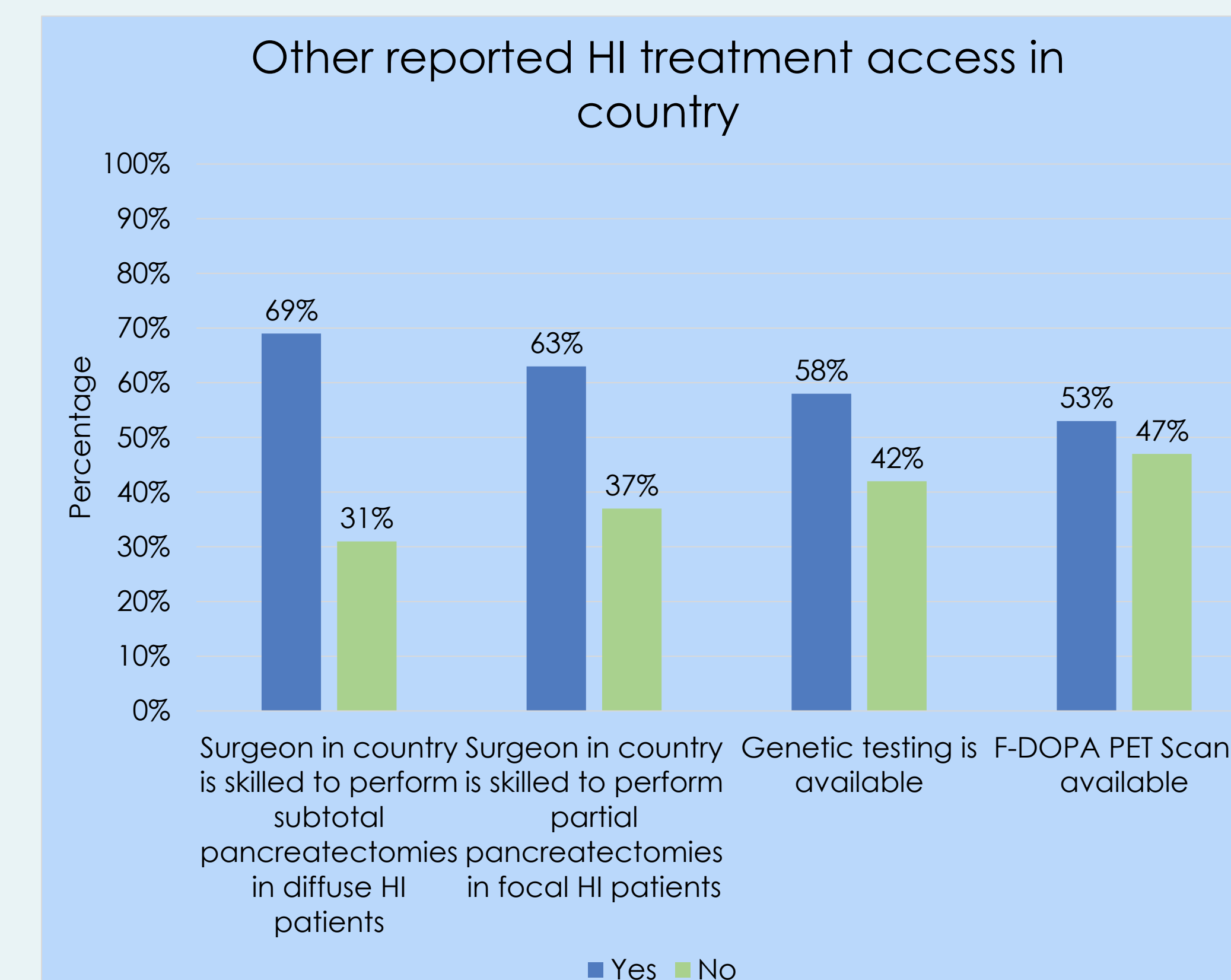
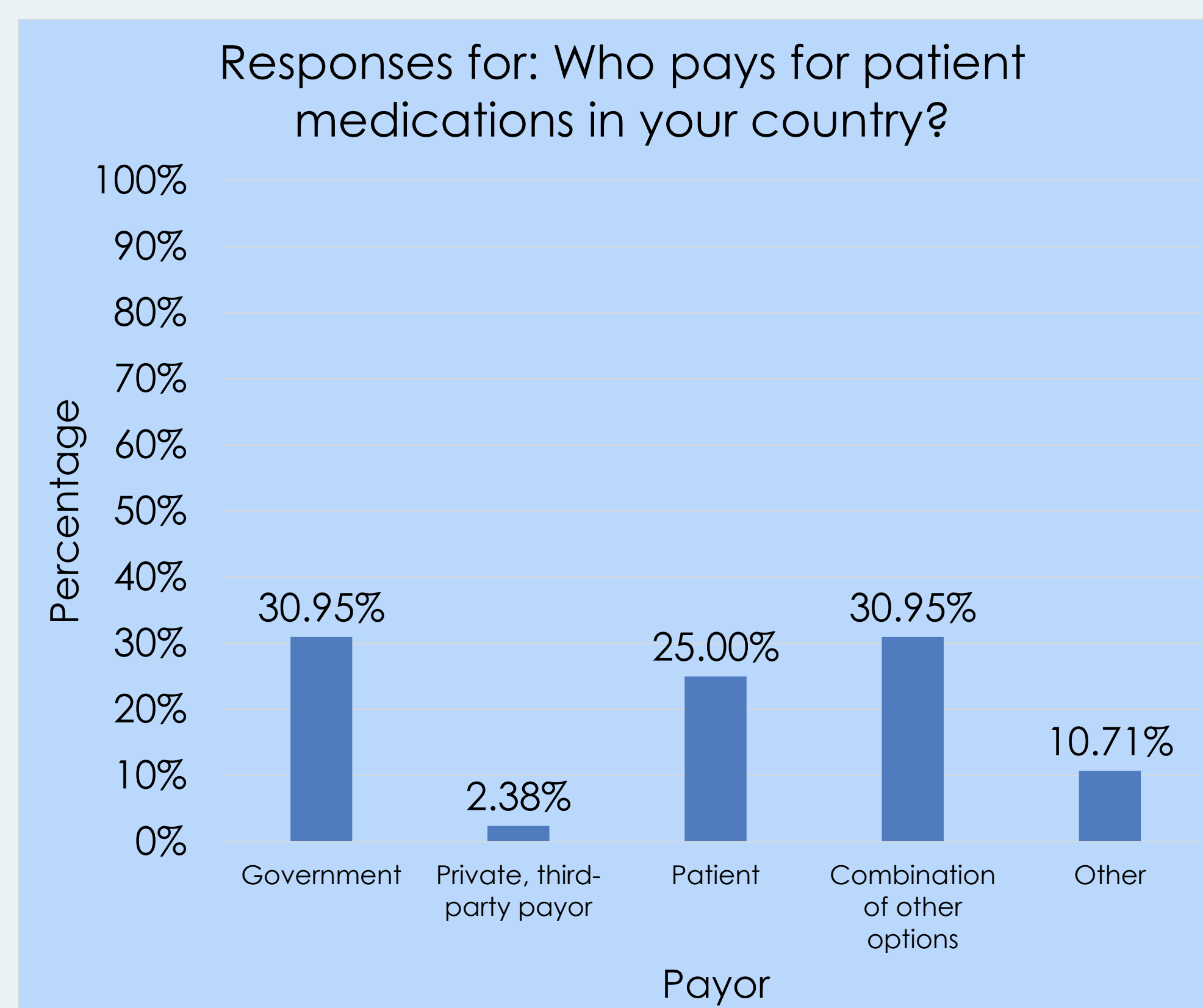
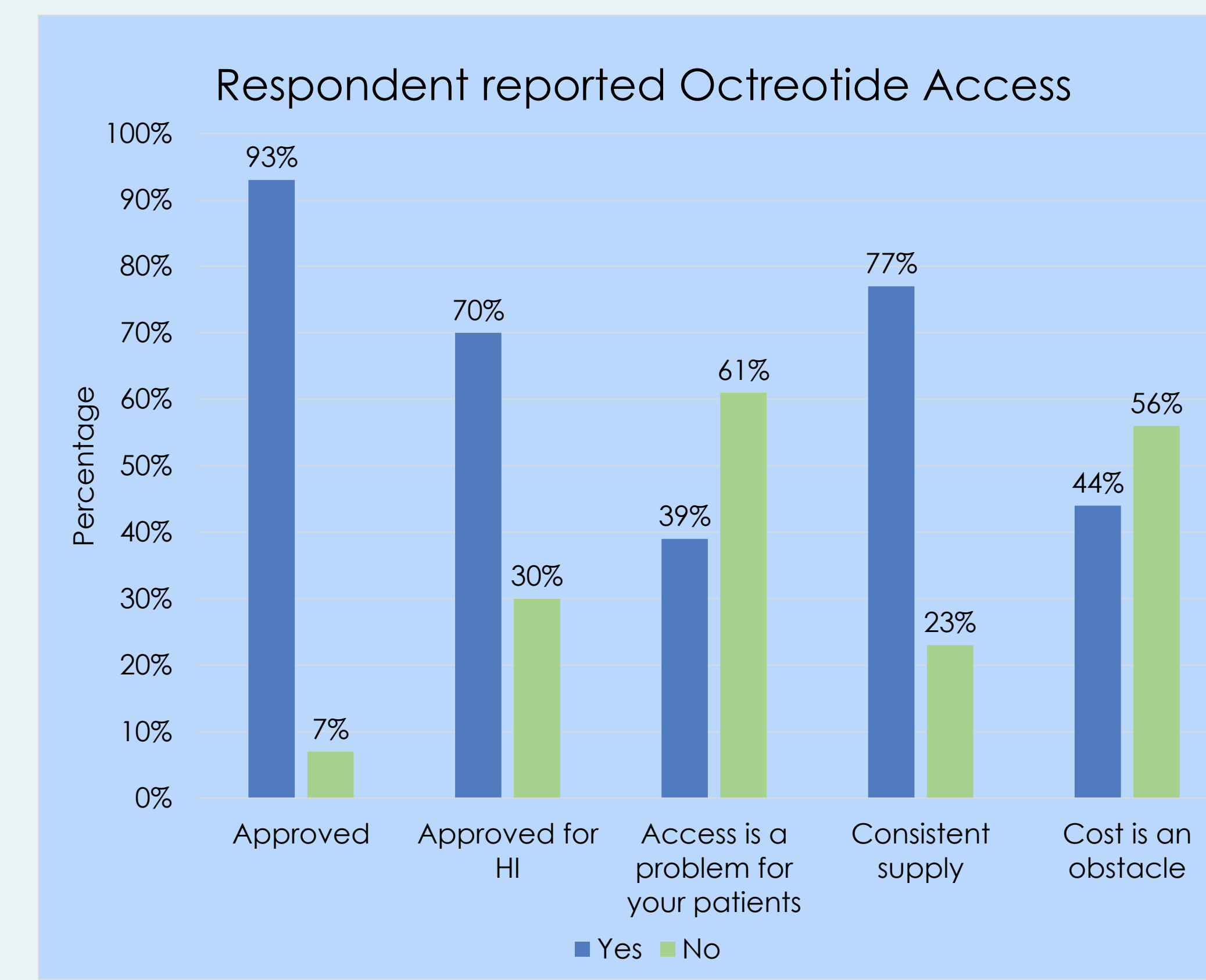
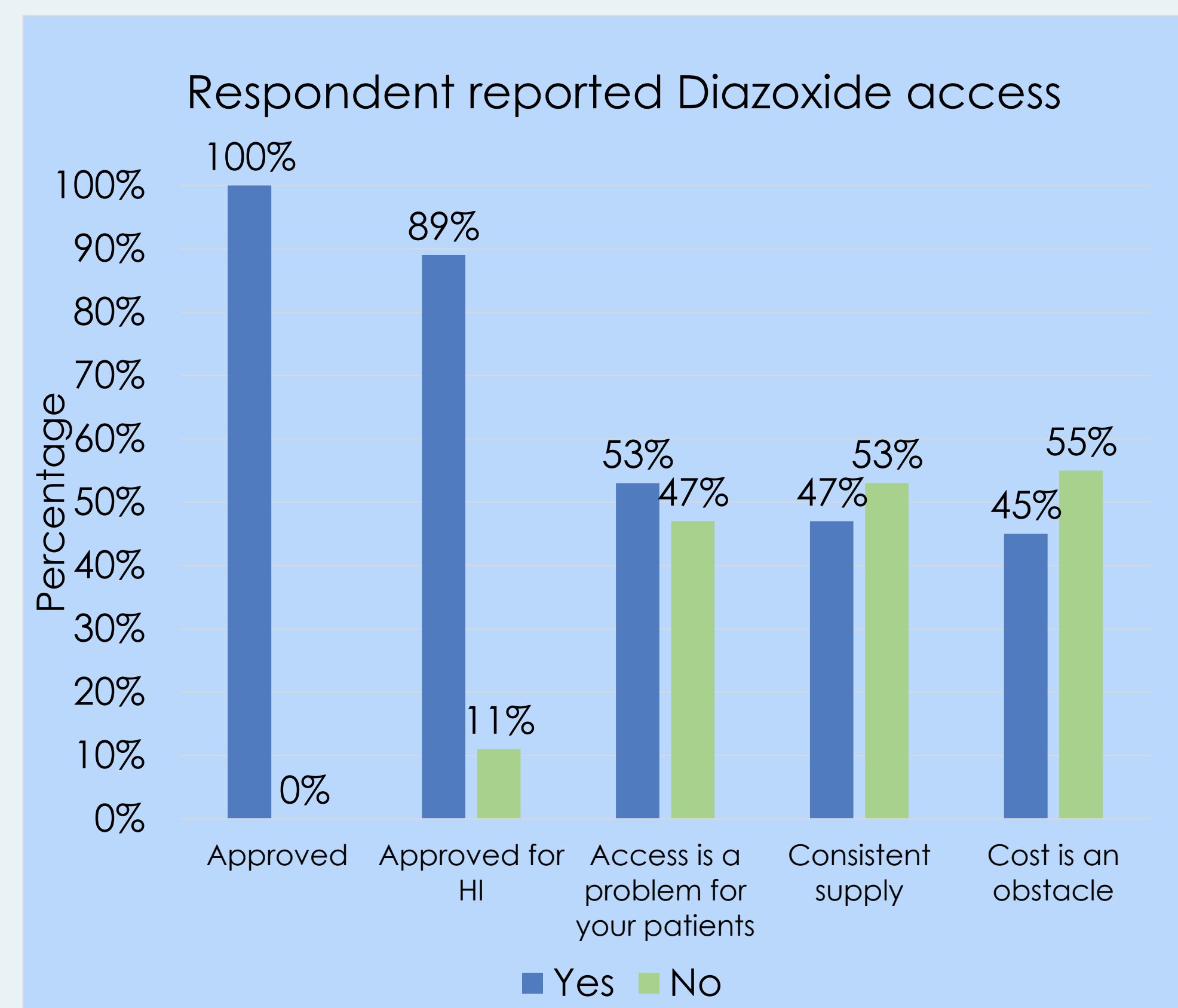
The Congenital Hyperinsulinism Global Access Survey was created in Survey Monkey and shared in October 2018. Responses were collected through January, 2019. The survey was globally disseminated to pediatric endocrinologists through CHI's email list. Descriptive and analytical statistics were reported.

Results

A total of 83 Pediatric endocrinologists from 46 different countries representing all continents participated in the survey. In some cases, physicians from the same country provided different answers to the same question, indicating additional variation to access within countries.

Respondents indicated that an average of 62% of their hyperinsulinism (HI) patients require diazoxide, an orphan drug approved for HI. Despite 77% of respondents stating that the drug was approved for use in their country, 64% indicated that their patients had a problem accessing the drug. The specific barriers identified were having a consistent supply of the drug (61% of respondents) and obstacles associated with cost (53%).

Figure 1: Countries Represented



Conclusion

Global access to HI care is inconsistent. It is critical to identify locations where patients are unable to access necessary treatment options. Especially in countries where endocrinologists report inconsistent access for patients. The results of this survey have been used to develop an international access strategy to increase the number of eligible patients who can benefit from available treatments, regardless of their geographic location.

Steps taken since research study

- In 2019, CHI joined the organization *Global Pediatric Endocrinology* in a successful application to have diazoxide included on the list of WHO Essential Medicines
- CHI continues to work with the organizations *Direct Relief* and *WEP Clinical* on donations of Proglycem/diazoxide to patients in countries where there is no access at all.
- A new generic version of diazoxide has come on the market in the US (2019, e5 Pharma) and in India (2020, Jolly, Diazoxide). CHI is working with these companies with the goal of expanding access to new countries.



DIAZOXIDE ADDED TO THE
World Health Organization
LIST OF ESSENTIAL MEDICATIONS