The PROBE Data Dashboard – A new tool for real-time data visualization and analysis of patient reported outcomes

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INTRODUCTION

The Patient Reported Outcomes, Burdens and Experiences (PROBE) Project developed a standardised questionnaire and a dedicated research network to generate and continuously update PROBE reference data. PROBE was developed with direct patient involvement through collaborations with non-governmental haemophilia patient organizations.

MATERIALS and METHODS

The PROBE data dashboard utilizes Microsoft Power BI software for business analytics. The first 2100 questionnaires collected in 21 countries were used to develop and locally test global and individual country dashboards. The psychometric properties of the PROBE questionnaire were assessed and a composite PROBE Score developed. Dashboard version 2.0 incorporates analytics to calculate the PROBE Score.

RESULTS

The dashboard is divided into two main components - filters and graphs (visualization views).

• Filters are divided into three subgroups such as personal, health problems and haemophilia related. Each subgroup allows refinement of the data sample for demographic variables (e.g., region of the world, diagnoses, disease severity, inhibitor history, treatment regimen).

• The visualization views provide graphic results for the selected outcome of interest (e.g., current health status, mobility aids, pain (including medication, acute and chronic pain), independence, joint surgery or another invasive procedure, employment and school life).

Comparator data from those not personally affected by a bleeding disorder are also depicted.

CONCLUSIONS

The results of the feature-rich dashboard indicate an integral interaction between the analytical tool Power BI and PROBE study data. The dashboard allows participating organizations easy, secure and large-scale external as well as internal access to PROBE study data. The properties of the PROBE questionnaire are suited for differentiating PWH with better or worse health status. The immediate use of the PROBE dashboard incorporating the PROBE Score will be in cross-sectional comparisons among different settings, e.g. different levels of care.

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(964x2341 to 2388x3037)

(82x1629) school life).

(2276x998)

(1017x1251 to 2273x1867)

(1134x2268) (Fixed for each page)

(1222x2309) (Multiple Pages)

(2002x2313)

(1811x2273) (Multiple Pages)

(1948x2273) (Multiple Pages)

(2536x143)

(2315x1804) FIGURE 1. PROBE STUDY DASHBOARD

FIGURE 2. PROBE DATA NAVIGATION

FILTER SEARCH

"Chronic Pain" dashboard page with filter search for patients who have ever been diagnosed with a clinically significant inhibitor. In our case, among 178 patients with clinically significant inhibitor, 74.16% reported chronic pain.

FILTER AND GRAPH SEARCH

Graphs as well as Filters can be useful search points to narrow down data in seconds. Filters are more permanent search tools while graphs can be temporary search tools.

(2120x23 to 2536x143)

(2333x984) (Multiple Pages)