

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.

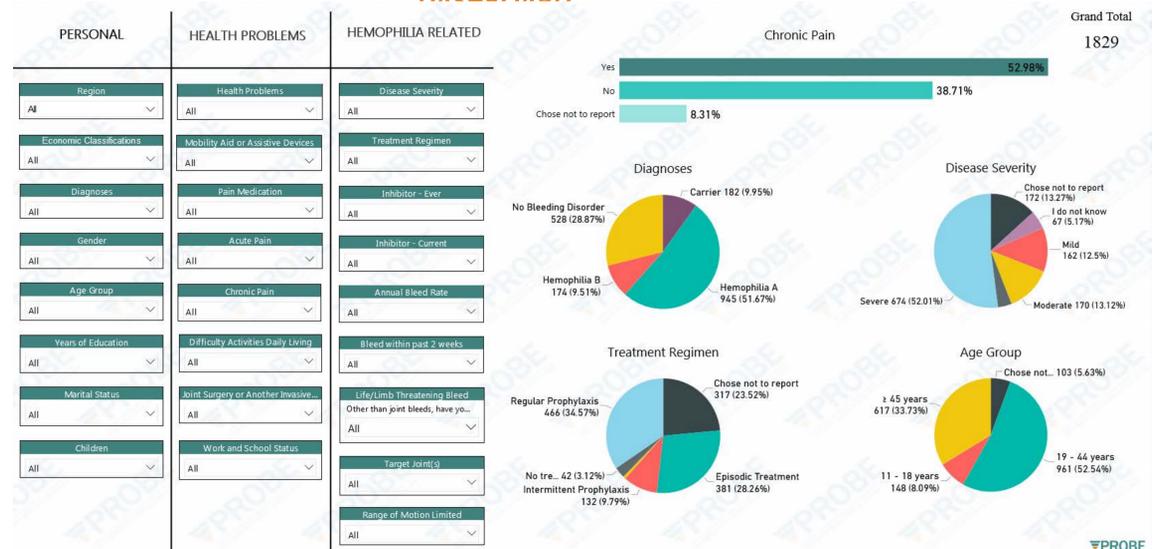
CONCLUSIONS

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.

ACKNOWLEDGEMENTS

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FIGURE 1. PROBE STUDY DASHBOARD



FILTERS (Fixed for each page)

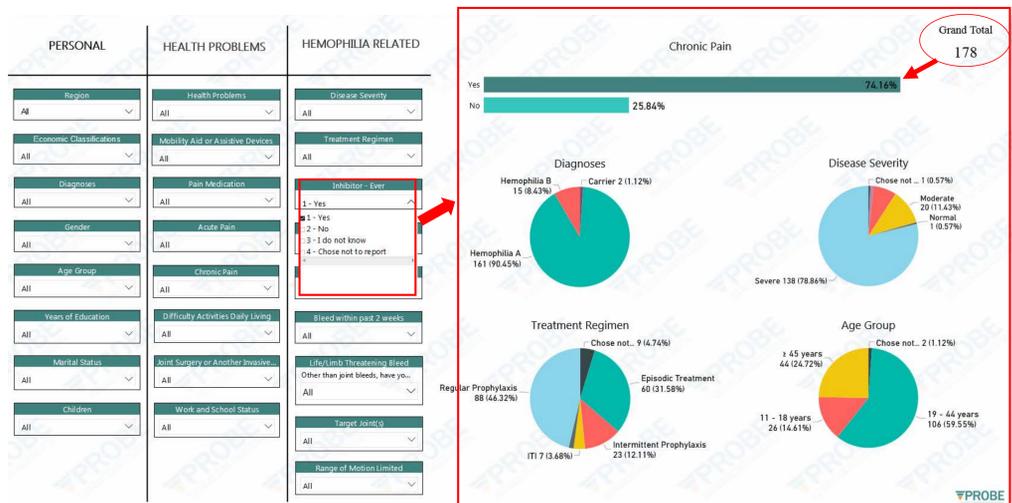
GRAPHS (Multiple Pages)

In the left column, refine the data set to the variables of interest by selecting filters of the three main categories (Personal, Health Problems and Hemophilia Related). Each category contains filter options to narrow your circle of interest.

The charts in the right column present a graphical visualization for the variable of interest. Charts will automatically adjust in response to search criteria selected in the left column.

FIGURE 2. PROBE DATA NAVIGATION

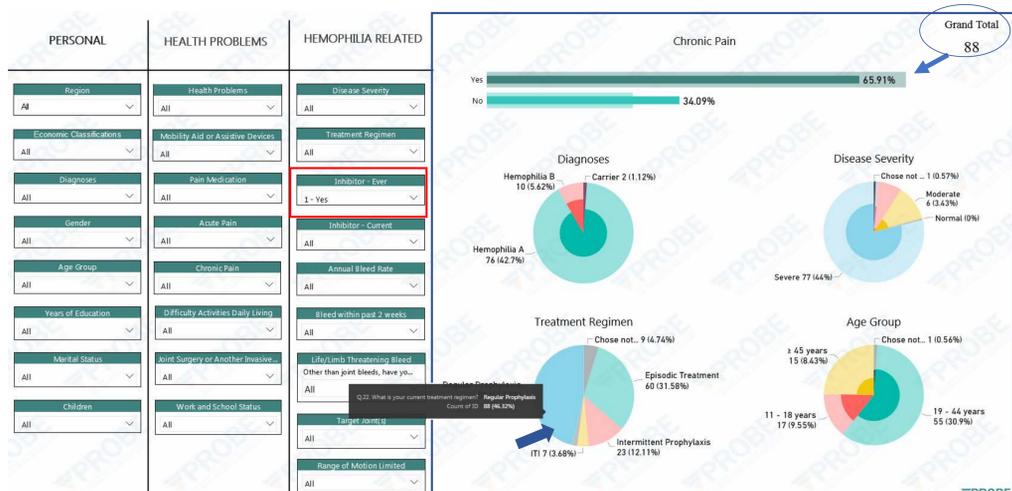
FILTER SEARCH



Filters and Graphs interact between each other depending on the area of interest.

"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.

Left click on "Regular Prophylaxes" on the "Treatment Regimen" pie chart will automatically lead to an adjustment to all graphs to a new selection. The dashboard shows us that 65.91% among 88 participants with clinically significant inhibitor on prophylaxes are having chronic pain.

For more information visit:
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