

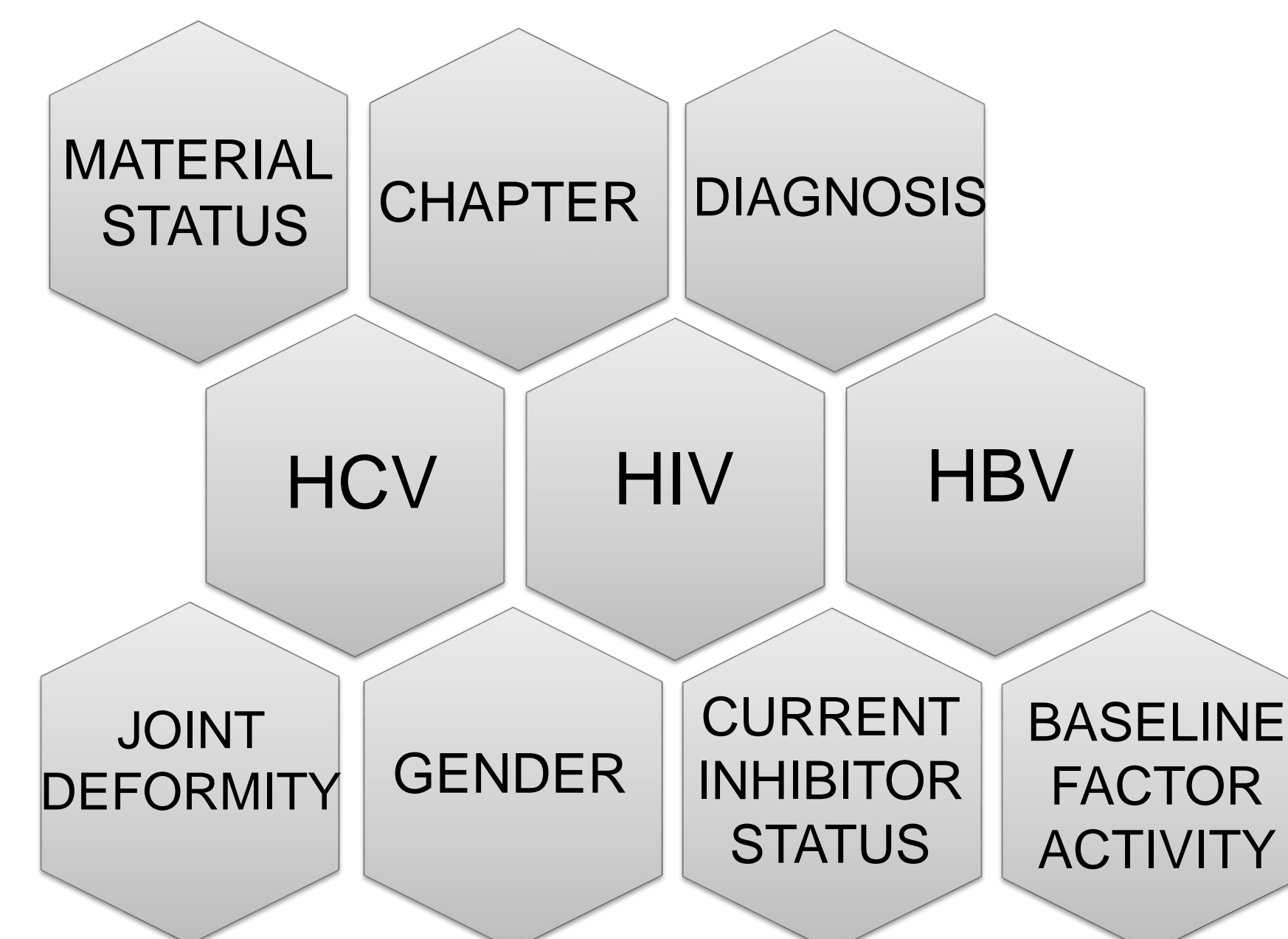
# Developing centralized web-based National Patients Registry: Pakistan's Experience

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## Introduction & Objectives

National Patients Registry for Pakistan is an effort to make centralized and reliable database of people identified with hemophilia, von Willebrand disease, and/or other inherited bleeding disorders. This is a web-based national level Patients Registry that can be accessed from anywhere and anytime. Pakistan Hemophilia Patient Welfare Society [PHPWS] collected data from different part of the country under WFH funded project in 2014, and later collaborated with NNHF to further strengthen this initiative by making it available online for an effective utilization. So as a next step, we developed an online run-time web-based software.

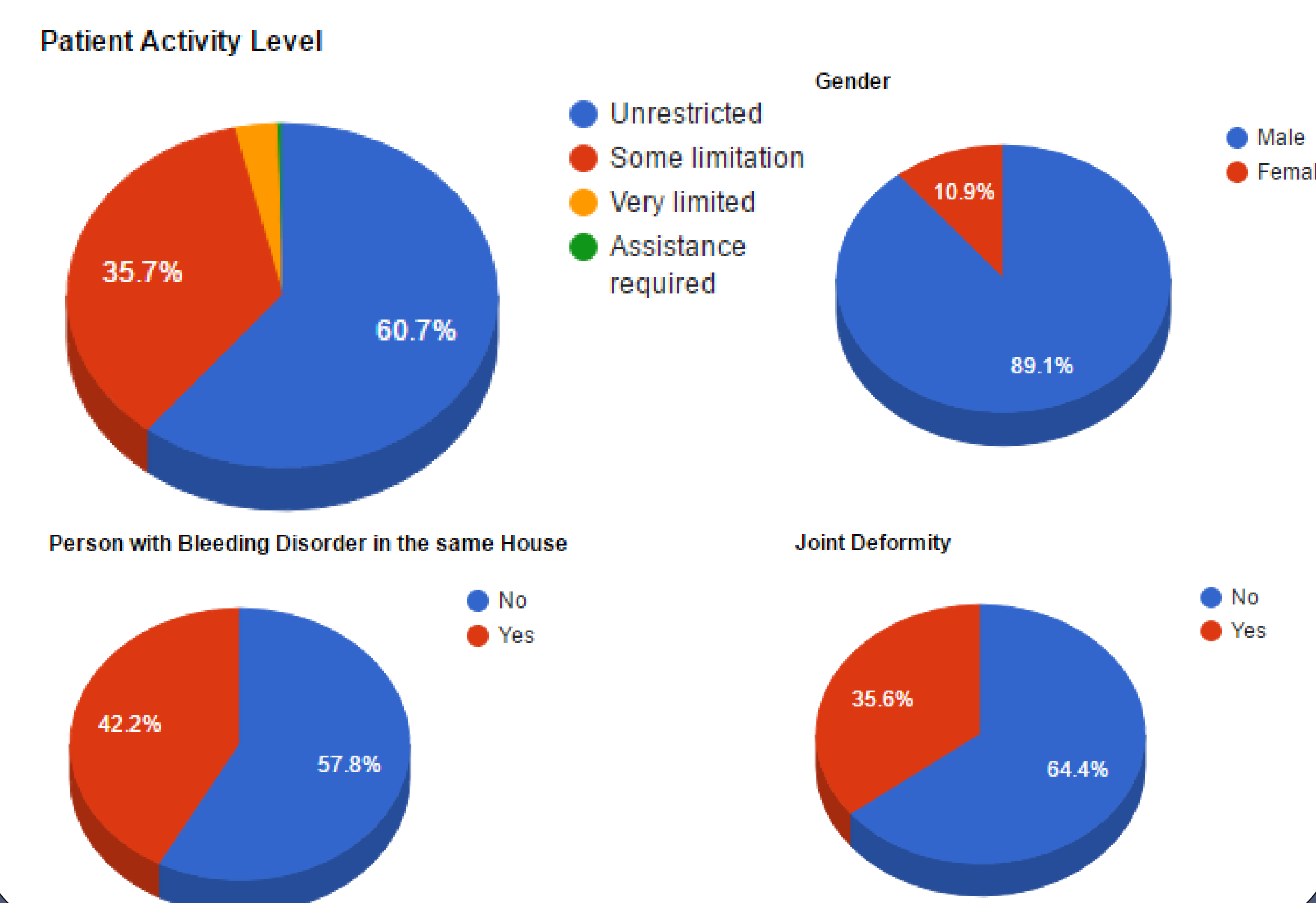
## Methods & Material



This "National Patients Registry" consists of both patient's information [demographic details] and Clinical part [diagnostic details]. By using the WFH's Global Survey format, we developed a standardized survey form [including patient's consent] through a consultative process. The whole process took months, which involved engagement of the leadership & patients, which provided guidelines to the software house. PHPWS-Chapters/HTCs are now entering data by themselves and the quality check of the data is managed at central level. During the development phase, all measures were taken in consideration to ensure confidentiality and data security.

## Results

This centralized Registry helped us in monitoring trends in health, allocating resources, priority setting, formulating policies, improving the purchasing process, serving as a distribution mechanism, establishing a communication network and ensured sustainability of the overall structure. In the past, PHPWS-Chapters were maintaining their own patient's record on papers which always sourced several difficulties, but now all the date is available on this web-based software that can be accessed [even through mobile devices] from any part of the globe.



## Conclusions

A patient-run registry can act as a catalyst in motivating and capturing attention of doctors, researchers and Ministries of Health. Such registry can also be an outreach tool – building a registry helps to build the patient community. Through enhanced features, it can map out geographical distribution of the community and provides insights with its various filters, to determine needs of members and forms basis for critical decision making. Such software and the simple procedure for updating records, further increases efficiency.

