

Clinical Management of Woman with Bleeding Disorders: A Survey among European Haemophilia Treatment Centres

van Galen et al. (2020)
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For which topic were research priorities identified?

haemophilia

In which location was the research priority setting conducted?

international

Why was it conducted at all?

The impact of bleeding for women with bleeding disorders (WBD) is of increasing focus and importance. Despite this, optimal management strategies are unclear and knowledge gaps persist. Despite increasing attention in recent years, medical knowledge on WBD lags far behind that of men with haemophilia. However, bleeding disorders in general affect men and women equally. In order to address this gender-related gap, the European Association for Haemophilia and Allied Disorders founded the Women and Bleeding Disorders Working Group in September 2018 (EAHAD-WBD working group).

What was the objective?

to examine practices and define research priorities on diagnosis and management of WBD in Europe

What was the outcome?

a ranking list of 8 research topics

How long did the research prioritization take?

May 2019 - July 2019

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: survey: open-ended questions on clinical knowledge gaps and research priorities for women with bleeding disorders. Step 2: data processing: thematic analysis

Which stakeholders took part?

European haemophilia treatment centers. Participants: 59 HTC's.

How were stakeholders recruited?

Participants were recruited via 136 European haemophilia treatment centres (HTCs).

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.