

EHC Position Paper on Women and Bleeding Disorders

Women with bleeding disorders face unique challenges that significantly impact their health and well-being, however, their needs are often overlooked due to a common misconception that bleeding disorders primarily affect men. Conditions such as haemophilia, von Willebrand disease, and platelet function disorders can cause severe health complications, including heavy menstrual bleeding, prolonged bleeding after injuries, and difficulties with childbirth. The hormonal fluctuations that occur during menstruation, pregnancy, and menopause can further complicate diagnosis and treatment. Understanding the complexities of bleeding disorders in women is crucial for early diagnosis, effective treatment, and improved quality of life.

Given the barriers that women with bleeding disorders face, the European Union (EU) needs to take proactive steps in addressing these gaps. We urge the EU to prioritise women's health by focusing on improving access to care, fostering research, and promoting early diagnosis and specialised care.

To ensure that women with bleeding disorders receive the care, attention, and treatment they deserve, the European Haemophilia Consortium (EHC) recommends:

Improving access to care

The EU should work towards ensuring equitable access to diagnosis and treatment for all women across all age groups and conditions. Many women face significant barriers to diagnosis and treatment, particularly in underserved or remote areas where specialised care may be scarce. The EU should invest in innovative healthcare delivery models, such as mobile health clinics, telemedicine services, and outreach programmes that ensure women and girls, especially in rural or marginalised regions, can access timely and effective care. These initiatives should also focus on reducing healthcare disparities for women and girls from low-income backgrounds or minority groups. The EU Pharmaceutical Legislation currently under revision should take the unique needs of women and girls into account when it comes to access.

Incentivising EU research

Currently, there is a significant gap in research focused on the gender-specific experiences of women with bleeding disorders. Women often experience different symptoms, such as more frequent or severe menstrual bleeding, that are underexplored in scientific studies. The EU should increase investment in research on women and rare bleeding disorders through Horizon Europe and other future EU research programmes. This research should also focus on developing tailored treatment approaches for women with varying severity levels of bleeding disorders.

Strengthening early diagnosis programmes

Early diagnosis is key to managing bleeding disorders effectively. However, women and girls are often misdiagnosed or diagnosed too late due to the overlap of symptoms with other common conditions, such as heavy menstrual bleeding. The EU must implement EU-wide initiatives to promote early diagnosis and intervention for women and girls with bleeding disorders. This could include awareness campaigns, screening programmes, and training for healthcare professionals (HCPs) to recognise the symptoms as early as possible.

Fostering multidisciplinary care

Women with bleeding disorders often require specialised care that includes multiple healthcare professionals, such as haematologists, gynaecologists, geneticists, and primary care providers. To address the complexity of their healthcare needs, we urge the EU to introduce an integrated care framework that incentivises holistic multidisciplinary care partnerships between haematologists and other providers of women's health within dedicated care centres.

Supporting data collection across the EU

To improve the understanding and management of bleeding disorders in women, the EU should encourage the establishment of registries and data collection systems that specifically capture women's health outcomes related to these conditions. Gender-sensitive registries would provide valuable insights into the prevalence, treatment, and long-term impact of bleeding disorders on women's health. This data, which could be facilitated through the European Health Data Space, can guide healthcare policies, improve access to care, and support research into more effective treatments and interventions.

Embedding Women's Health in EU policy

As significant changes in EU health policy are happening now, including the revision of pharmaceutical legislation, the EU Critical Medicines Act and implementation of EU HTA regulation and the European Data Space, it is crucial that these policies are designed to prioritize the health of women with bleeding disorders across the EU. Gender mainstreaming should be applied in all EU health policies to ensure that the specific needs of women with bleeding disorders are fully addressed.

The challenges faced by women with bleeding disorders are real, significant, and often overlooked. By improving access to care, incentivising gender-specific research, strengthening early diagnosis programmes, fostering multidisciplinary care, and supporting data collection, the EU can help ensure that women with bleeding disorders receive the comprehensive care they need and deserve.

The European Haemophilia Consortium (EHC) calls on EU policymakers to take action to address the healthcare disparities faced by these women, with the aim of improving their health outcomes and quality of life.