

Chapter 11: Outcome Assessment

Pradeep M. Poonnoose, Brian M. Feldman, Piet de Kleijn, Manuel A. Baarslag, Radoslaw Kaczmarek, Johnny Mahlangu, Margaret V. Ragni, Glenn F. Pierce, Alok Srivastava

RECOMMENDATIONS

11.2 | Frequency of bleeding

Recommendation 11.2.1

For providers of care for people with hemophilia, the WFH recommends ensuring that the frequency of all bleeds is documented in real time by patients/caregivers and reviewed together at least annually, with particular reference to intra-articular, intramuscular, and central nervous system bleeds, including their recovery status. Standard criteria defined by the Scientific and Standardization Committee of the International Society on Thrombosis and Haemostasis should be used. ^{CB}

11.7 | Health-related quality of life

Recommendation 11.7.1

The WFH recommends assessing and documenting the musculoskeletal and overall health of each patient at least annually. This should include an assessment of body structure and function, activity levels, participation and health-related quality of life as per the World Health Organization's International Classification of Functioning, Disability and Health (WHO ICF), as much as possible, in the right clinical context.

- REMARK: Standard definitions and validated tools should be used as much as possible, including the following:
 - For body structure and function, clinical assessment of joints is (most) commonly done using the Hemophilia Joint Health Score (HJHS) in both children and adolescents.
 - Under the same domain, early structural changes in joints are best assessed using ultrasound (US) or magnetic resonance imaging (MRI). Late osteochondral changes may be assessed on plain radiographs.
 - Functional activity levels should be assessed using the most appropriate option available for that individual, including the Haemophilia Activities List (HAL), the Haemophilia Activities List for children (PedHAL), or the Functional Independence Score in Hemophilia (FISH).
 - HRQoL is an important aspect of outcome measurement that may be assessed using either generic or disease-specific tools, but only in combination with the other domains of the WHO ICF. ^{CB}