

1. Hospitals providing clinical care for people with haemophilia and related disorders are strongly recommended to seek formal designation as either EHCCC or EHTC. (Access to comprehensive care and replacement therapy should be equitable in all parts of a country).
2. There should be agreed national protocols or guidelines on management of the ageing patient with haemophilia. Treatment centres are encouraged to include an appropriate general physician in the comprehensive care team.
3. The minimum consumption of factor VIII concentrate in any country should be 4 iu/capita of general population. (Data expressed as units/severe patient should also be collected in parallel in future.)
4. The minimum consumption of FIX concentrate in a country should be 0.5 iu/ per capita of general population.
5. Treatment for hepatitis C with direct-acting antiviral agents should be provided to all people with haemophilia on a high priority basis.
6. Genotype analysis must be offered to all patients with severe haemophilia and the results used to identify carriers in the wider family.
7. People with inhibitors should have access to immune tolerance.
8. People with inhibitors should also have access to elective surgery at a specialist centre with relevant experience.
9. National or regional tenders for factor concentrates are encouraged and should always include both haemophilia clinicians and national haemophilia patient representatives.
10. Outcome data including health related quality of life should be collected with appropriate study design, e.g. annualised bleed rates (ABR), mortality, joint score and time off education or employment.
11. Treatment with extended half-life factors should be individualized and protection against bleeding should be improved by increasing trough levels.
12. There is increasing evidence that the incidence of inhibitors amongst previously-untreated patients (PUPs) varies between products. Steps should be taken to understand and minimise this risk. (Patients, or their parents, should be involved in discussions related to product choice.)

