Text box 1: Important points from the history

Important points to be obtained in the history

Date of diagnosis

Presenting symptoms and signs at diagnosis

Hemoglobin prior to first transfusion

Date of first transfusion

Date of initiation of regular transfusions (8 or more transfusions /year)

Reasons for initiation of regular transfusions, if applicable

Transfusion history including regular update of number of transfusions received to date

Year of initiation of iron-chelating therapy if applicable

Initial clinical parameters at initiation of iron-chelating therapy

Year of, and indication for, splenectomy if applicable

Compliance with medication

Age at menarche (and mother’s age at menarche if available)