

**CLL Autograft Trial – Quality of Life Study**  
**Role of the Co-ordinating Centre and Central Co-ordinator.**

1. For each country there should be a CO-ORDINATING CENTRE with a CENTRAL CO-ORDINATOR, who will receive all completed questionnaires from patient entered from all the local centres in that country.
2. The CENTRAL CO-ORDINATOR will have access to the appropriate QoL Questionnaires on the Web Site, and may be required to download and print copies of the questionnaires to send to the centres at their request. (See *Quality of Life Questionnaires – General Guidelines* and *Standard Procedure in the Local Centres*)
3. The CENTRAL CO-ORDINATOR and the LOCAL CENTRES should decide between themselves how the questionnaires are to be produced in their own country and who is responsible for providing the reply paid envelopes
4. The CENTRAL CO-ORDINATOR will check that each centre holds at least two paper copies of the BASELINE questionnaire ready to be issued when a patient is randomised into the trial.
5. The CENTRAL CO-ORDINATOR will record receipt of completed baseline questionnaires from the patients.
6. He/she will check through the questionnaire for any comments made by the patient and see that they are translated into English, and then will send the completed baseline questionnaires to the data centre in Leiden.
7. The CENTRAL CO-ORDINATOR will receive notification of follow ups due in each centre via Leiden one month in advance of the due date, and will either produce the correct questionnaire from the website to send to the centres for those patients, having entered the appropriate trial number on the front page and indicated the correct month of follow up due, or instruct the centres to produce the questionnaires with these details entered to give to the patients at the correct time.
8. Receipt of completed follow up questionnaires should be recorded, and the questionnaire checked for any comments made by the patient. These comments should be translated into English
9. The completed follow up questionnaires should then be sent to the data centre in Leiden
10. Please take note of any questionnaires not received within six weeks of sending out and chase the centre for these – either to encourage the patient to complete and return the questionnaire, or to give reasons why that may not be possible. (e.g. patient refusal, too ill, dead, etc) An Investigator's Form (follow up) is available on the Web Site for this purpose, which should be returned to the data centre in Leiden after completion.