

# ENRAH for SMEs Project

## Glossary to the Questionnaire for the AHC Registry:

Version 1.0, July 2006

### 1. Introduction:

Please consult this glossary before you start collecting the data in order to guarantee a universally valid assessment of data.

### 2. Person-Identification, Center Identification, Date:

“Patient Code provided by the center”:

Is intended for local use, independently from when the data will actually be entered in the Registry.

G0.0 “Patient HC Forum Identifier”:

Is the code for Patient-Identification which will be automatically assigned to the patient when you start entering data in the Registry.

Details about the use of Patient Code and HC-forum Identifier:

When the rater starts to collect the data (fill the questionnaire) he should assign the (local) Patient Code, according to his own coding system, and use it to label each page of the questionnaire. Afterward, when he transfers the data into the Registry, he will have to copy the HC Forum identifier in the first page of the questionnaire.

Thus, the local database (paper questionnaires or WORD files on a PC) will contain the link between the local code and the HC FORUM identifier; the link between the personal data of the patient and his/her anonymous identifier (local code and/or HC Forum Identifier) must be kept separately in a secured place.

G0.2 “Date of Inclusion into the Database”:

The date of the day when the ENRAH Reference Center starts to collect the data.

### 3. Fill-In Rules:

Narratives should be very short, please use keywords, if possible

For the Follow up Forms:

Please do always read **all** the questions of a paragraph before you answer the headline-question with either yes or no.

As soon as a headline question has been answered with yes all the following questions in a paragraph have to be answered.

#### **4. Terms used:**

F1.1.1, F1.2.1, F1.3.1 "Semiology":

Clinical picture or clinical appearance of symptoms

- Simple : Uniform sensorymotor / psychic symptoms

Any possibly relevant information that could not be attributed to one of the sections above.

If you want to quote drugs, please fill in their generic names in English. In case there are drugs and other items, please try to quote drugs first, in order to facilitate retrieving of text from this field.