

## RightTimePlaceCare Project Meeting with Praxis Partners on 7th June 2011

### Results of the discussion on “Looking for Participants”.

The following shows a summary of the results of the discussion.

#### 1. Inclusion Criteria

- The list of present clients or of new residents should be examined regularly and checked carefully with regard to the inclusion criteria. It is helpful to have a permanent project representative with defined responsibilities.
- The inclusion criterion “*Diagnosis Dementia*” can be problematic if there is certain evidence pointing to dementia but a doctor has not yet defined the diagnosis.

Suggested solutions:

- Contact the family doctor/general practitioner to obtain the diagnosis. At the same time the doctor should receive a short explanation informing him about the RightTimePlaceCare project. We are enclosing a checklist to assist with this.

#### **In the home care sector:**

- The inclusion criterion “At risk of having to move into a residential institution within the next 6 months” does not mean that the move actually has to take place. We are asking for a professional assessment as to whether this could happen (e.g. dangerous situations are increasing, the person with dementia is alone more often, the informal carer is ill). We shall of course treat this assessment absolutely confidentially; the informal carer will naturally not be informed.

#### **In the residential care sector:**

- In order to take part in the survey, the resident should not have been living in the institution longer than **three months**. The first of the two interviews should take place within this period, the second should follow three months later.

## **2. Getting the informal carer's consent to the interview**

### **When is the right moment to inform the informal carers?**

- It is better not to inform them directly after the move into the nursing home.
- After they have received the first information, they should have time to think it over. A few weeks later they should be asked again for their decision. There is three months' time after moving in for the first interview to take place.
- Patients receiving short-term care should be approached later when it is certain that the move into the nursing home will be permanent.
- New clients in the home care sector should also be allowed time for consideration (phone calls after a while).

### **How should the informal carers be approached with regard to the project?**

- Mention that the interview can take place wherever the informal carer may wish (in the nursing home, at his/her own home or at the University Witten/Herdecke).
- The interview is always voluntary and can be broken off at any time.
- Describe the contents and duration of the interview, mentioning the timing involved: Call from a member of the UWH, then the first interview, followed by the second interview after three months. We are enclosing an additional outline of the sequence and contents of the interview.
- Make it completely clear that the interview is important and that in future care management could be improved, not only in Germany but throughout Europe.
- The informal carers are experts who matter and their experience is extremely important for research!
- Leaflets are helpful and can be handed over during a conversation.

## **3. Gathering experience**

### **With the informal carers in the interviews:**

- The informal carers often experience the interviews very positively and enjoy having the opportunity of talking and being able to reflect on their situation.
- They often feel themselves "in good hands" and are able to confide in a neutral person.

### **With the professional carers (who give the interviews in the nursing homes)**

- The interviews are also an opportunity for the professional carers in the nursing homes to interrupt their "work routine" and to reflect on their work with people with dementia.