GENERAL INSTRUCTIONS

Purpose

The purpose of the RUD© instrument is to collect data on resource utilization in order to calculate costs of patient care (healthcare resource utilization) and caregiver time in Dementia.

Participation in data collection process

The patient
Due to their dementia, the patients themselves can seldom answer specific questions about their resource utilization, particularly since the timeframe for collecting information on many of the questions may span a period of 3 months prior to the interview (therefore requiring a good episodic memory). Consequently, the caregiver will be the informant and the patient will give consent for the caregiver to report on healthcare resource utilization and caregiver time on his/her behalf.

The primary caregiver
The primary caregiver participating in this data collection is the caregiver who has been accepted to participate in the study and has signed an Informed Consent form to provide data on his/her demographics, patient and caregiver resource utilization and time spent with the patient.

Change in caregiver
If the caregiver participating in this data collection can no longer participate (due to illness, death, moving, etc.), a new caregiver will be sought and asked to consent to provide data on his/her demographics, patient and caregiver resource utilization and time spent with the patient.

Completion of the questionnaire

The RUD© is to be administered as an interview with the caregiver. The interviewer is the research nurse or another staff member involved in the study who has been trained to administer the RUD©.

The caregivers of all ongoing and new patients will be administered the RUD©. The RUD© will be administered in the course of a regular study visit.

Several of the questions asks for the number of times, visits, hours etc. They are followed by a place holder to report the answer and a “none” tick box which should be ticked if this resource was not used at all. If this box is ticked, the place holder can be left blank.
SPECIFIC INSTRUCTIONS

There are 2 slightly different RUD© questionnaires to administer:

The Baseline Questionnaire is to be used the first time the RUD© is administered to a caregiver.

The Follow-Up Questionnaire is to be administered at every subsequent visit.

The RUD© instrument is divided into 2 sections:

- A section designed to capture information on the primary caregiver, his/her healthcare resources and his/her time spent with the patient.

- A section designed to capture information on the patient and his/her utilization of healthcare resources.
A. BASELINE QUESTIONNAIRE

Indicate on the case report form which visit week the RUD© Baseline Questionnaire was administered to the caregiver.

The recall for all items in the baseline questionnaire is the last 30 days.

A1. CAREGIVER

A1.1. Description of Primary Caregiver

Note that if the caregiver is a healthcare professional (e.g. a nurse in the case where the patient is living in a nursing home), then leave questions A1.1.4. to A1.1.7 blank.

Question A1.1.6 refers to other informal caregivers.

A1.1.2. Caregiver Time

This section concerns informal caregiver time. Caregiver time is reported for the period of the previous 30 days. Note that in this section, only the time spent by the primary caregiver should be considered.

A healthcare professional is not considered as an informal caregiver in this version (however, this may be the case in RUD Inst and in studies with another design). Consequently, if the primary caregiver is a healthcare professional, please do not answer questions A1.2.1 to A1.2.4 on caregiver time.

If the primary caregiver is not a healthcare professional, but is paid totally or partially for the time spent caring for the patient, indicate the total time for both the unpaid and paid care periods.

Time spent by other people who are hired and paid should be reported in section A2.2.5. Examples include nurses, home aids, volunteers, hired friends, etc.

Caregiver time may be classified according to the three following categories:

1. Personal ADL (Activities of Daily Life) such as toilet visits, eating, dressing, grooming, walking, and bathing.
2. Instrumental ADL, such as shopping, food preparation, housekeeping, laundry, transportation, taking medication, and managing financial matters.
3. Supervision (or surveillance), which is related to the prevention of dangerous events, such as risks of fire, walking onto a road alone, walking outside without appropriate clothing for cold weather, etc.

Two questions are asked for each of these categories. The first question (a) refers to how much caregiver time is spent during the previous 30 days, while the second question (b) refers to the number of days that care was provided during that period. For example, if a daughter makes 16 visits to her demented mother during the previous month and spends 2 hours on average at every visit helping her mother with her personal ADL, then the answer to 2a is “2” and the answer to 2b is “16”.

The total time should be divided between the time spent assisting in personal ADL, Instrumental ADL (IADL) and supervising activities, according to the proportion of time spent assisting the patient in each activity.

Note that the number of hours of caregiver time for any given day cannot exceed 24 hours. For instance, if the caregiver is awake during 18 hours and supervision is needed for all of these 18 hours, but the time spent that day on IADL is 4 hours, then the estimated supervision time is 14 hours.
Further, the number of days per 30 days spent on caregiver activities may also vary across the different types of caregiver activity categories (example: there may be support in personal ADL on 4 days/week, supervision every day and Instrumental ADL-support only once a week).

In rare circumstances, if the amount of care varies from day to day, it could be that e.g. the caregiver provides instrumental ADL 14 hours per day two days per month and personal ADL 13 hours per day during five days per month, this would also be an acceptable answer. Observe however that the total number of hours per 30 days cannot possibly exceed 24h x 30days (720 hours). In the above example the number of hours would be 14x2+13x5 < 720.

A1.2.1. Sleep
Ask the caregiver how much time per day and night they spend asleep. This information is used in analysis to set the maximum time available for care.

A1.2.2. Personal ADL
State the time spent on personal ADL.

A1.2.3. Instrumental ADL
IADL activities are often performed for more than one person. For example, a spouse prepares food during 3 hours for both the patient and himself/herself. If this is the case, divide the time spent by two, i.e. caregiver time of 1 hour and 30 minutes.

IADL activities also often occur irregularly. If the caregiver assists the patient in shopping for 2 hours each week, then the answer is 2 hours for question 3a and 4 days for question 3b.

A1.2.4. Supervision (or surveillance)
Sometimes the caregiver perceives they are supervising the patient around the clock. If so, the interviewer can use the following probe questions to help estimating actual time: Can the patient be left alone for part of the day? If so, for how many hours? Can the patient be left alone at night? Ask how much time the caregiver spends asleep. The total time spent on care should not be more than 24h minus the time spent asleep per day.

Supervision time includes the total time spent supervising the patient, whether or not supervision is related to the patient’s dementia per se.

A1.3. Caregiver Work status

A1.3.1. Working for pay
State whether the caregiver is working for pay or not.

Sick-leaves should be reported in the following way: sick-leaves of less than or equal to 1 month (1 month = 30 days) are regarded as ‘working for pay’ (Answer “Yes” to question A1.3.1.) while sick-leaves of more than 1 month are regarded as ‘without pay’ (Answer “No” to question A1.3.1 and answer “Own health problems” on the next question A1.3.2.).

A1.3.2. Reasons for being off work
If the caregiver is out of the work force, indicate the reason why.

Early retirement
This includes different types of early retirement (before regular retirement age), that are not due to illness. Examples of early retirement include retirement negotiated with employers, insurance pension retirement, etc.
Own health problems
Early retirement due to illness, or sick-leaves of more than 1 month.

To care for patient
Includes situations where the caregiver has stopped work, whether or not he/she is paid to care for the patient.

A1.3.3. Work time per week
This time should include all work for pay, also if part of the work is paid work to care for the patient.

A1.3.5. Reduction of working time
This question focuses on planned reductions in regular work time whereas the next question A1.3.6 considers occasions when the caregiver has missed time off work due to unexpected events.

A1.3.6. Unscheduled missed days of work
This question considers occasional episodes which do not influence the regular working time, for instance when the caregiver must leave work because the demented has lost her/his way. If there has been both occasional events (question 6) and a change in regular work time because of caregiving responsibilities (question 5), then register at both, otherwise do not double register.

A1.4. Caregiver health care resource utilization

A1.4.1. Hospitalization times
A hospital admission is defined as an admission to an acute care hospital, which includes an overnight stay. State the number of times the caregiver was admitted.

A1.4.2. Hospitalization nights
State the total number of nights in each ward. If the caretaker was hospitalized 3 times (3, 2 and 5 days) in surgery, combine and sum up all admissions (10 days).

A1.4.3. Emergency room/casuality ward visits
If the caretaker visited an emergency room and then returned back home without being registered as an inpatient at a hospital, then note the number of such visits here. Emergency visits to primary care centers should be noted in section A1.4.4.

A1.4.4. Outpatient care visits/clinic visits
This can be both visits by the patient to the clinic (or similar) or visits in the caretakers home.
A2. PATIENT

A2.1. Patient Living Accommodation

A2.1.1. Permanent Living Accommodation/"Usual Living"
Care institutions and other types of accommodation for the elderly vary between countries and the following “definitions” serve as a guide for the classification of the accommodation. Although classification of the patient’s accommodation may be difficult, you must choose a single and most representative category.

In the case where there doesn’t seem to be a “permanent” living accommodation, consider the current living accommodation as being the permanent accommodation and consider other accommodations as temporary in the context of this questionnaire.

Own home
Describes a ”usual living” environment that may be an apartment (flat), a house or a similar dwelling that was not originally designed for patient care. This includes housing where some adjustments may have been made to accommodate for the patient’s care needs.

If the patient lives in the same house as, for instance, his/her son, and the house is owned by the son, the patient’s living accommodation should be classified as “own home”.

Intermediate forms of accommodation (not dementia-specific)
A permanent residence where the patient lives in his/her own apartment. The apartment fulfils criteria for private living in physical terms. Home service is available from staff in the home, but the staff/patient ratio is lower than in nursing homes. There are few or no medical-technical equipment available. While there may be care staff members present during the night, their numbers must be limited. This kind of living environment is sometimes referred to as “Home for the Aged/Old People’s Home”/Assisted Living. Day Care activities (see section A2.2.5.) may be available in the building.

Dementia-specific residential accommodation
Note that it is the manner in which the care and living environment is organized that is important in differentiating between “not dementia specific” and “dementia specific”, since there may also be demented patients living in “not dementia specific” accommodations.
This type of accommodation is characterized by a group living environment (e.g. group homes, group dwellings, collective living, and similar). This is a permanent residence for 4-10 demented people, where each person lives in his/her own room or a small apartment and where facilities/rooms for common activities such as meals and other social activities are available. Staff members are trained in dementia care and are available around the clock. Staff members provide supervision and care for the demented patients according to specific goals for dementia care. The specific goals may vary but are mostly based on guidelines for nursing in dementia care (such as managing behavioural disturbances, apraxia, agnosia and memory impairments). Staff may include nurses, licensed practical nurses (assistant nurses), home aid personnel, or special dementia care people.

Long-term institutional care/nursing homes
These are care units where nursing care is provided around the clock to those who are chronically ill and unable to perform daily activities. Staff may include nurses, licensed practical nurses (assistant nurses), and orderlies. Staff members are available around the clock. Medical-technical equipment is available. The care environment is often referred to as a “nursing home”. Special care units located in nursing homes also belong to this category.

Other
A permanent living accommodation that doesn’t correspond to the above options must be specified.
A2.1.3. Temporary changes in living/Respite care
This question deals with short-term/temporary care accommodation or respite care (which differs from emergency hospital care). If there are difficulties differentiating between, for instance, nursing home care and short-term care in nursing homes organized by geriatric clinics, classify the temporary accommodation as long-term institutional care.

This question allows you to report several changes in the patient’s living accommodation since the last 30 days. The important information is the number of night(s) spent in each accommodation. If any one type of accommodation has not been used, simply answer “0”.

A2.2. Patient Health Care Resource Utilization

A2.2.1. Hospitalization times
A hospital admission is defined as an admission to an acute care hospital, which includes an overnight stay. State the number of times the caregiver was admitted.

A2.2.2. Hospitalization nights
If the patient has been admitted to a hospital during the last 30 days, enter the total number of nights spent in each ward. If the caretaker was hospitalized 3 times (3, 2 and 5 days) in surgery, combine and sum up all admissions (10 days).

A2.2.3. Emergency room/casualty ward visits
If the caretaker visited an emergency room and then returned back home or to the long term care institution without being registered as an in patient at a hospital, then note the number of such visits here. Emergency visits to primary care centers should be noted in section A2.2.4.

A2.2.4. Outpatient visits/clinic visits
This can be both visits by the patient to the clinic (or similar) or visits in the caretakers home. Avoid double registration here (occupational therapists and physiotherapists) and in section A2.2.5 (day care with occupational therapists and physiotherapists available). If it is a specified day care activity, then note it in section A2.2.5.

A2.2.5. Other resources and services
If number of hours is not applicable leave this field blank but make sure to state the number of visits.

Registered nurse home visits/district nurse
All types of home visits by registered nurses or similar personnel (nurse title can vary).

Nursing services provided during the study (“study visits”) are not to be included in section A2.2.5 of the questionnaire.

Home health aid/orderly/home help/health care assistant
Also include visits by licensed practical nurses/assistant nurses here.

Food delivery/meals on wheels
Only include publicly/insurance paid delivered meals.

Day care
The term “day care” (other names may vary in administrative terms) broadly refers to caring activities that occur in special care units and where the patient does not participate in an overnight stay.

For instance, the following types of day care should be noted as “day care”. 
Day care for demented patients: specific settings where staff members provide supervision and care to demented patients according to specific goals for dementia care, mostly during 5-7 hours/day. The specific goals may vary but are mostly based on guidelines for nursing in dementia care (such as managing behavioural disturbances, apraxia, agnosia and memory impairment) and the staff members are trained in dementia care. Staff members may include nurses, licensed practical nurses (assistant nurses), home aid personnel, or special dementia care people. The patients mostly come from their own home but may also come from homes for the aged or other accommodations. In most instances, 2-3 staff members serve 7-12 demented people.

Day Care focused on physical disabilities. Patients receive care at a particular location, mostly during 5-7 hours/day according to goals that are focused mainly on rehabilitation and physical training. Staff members may include nurses, physiotherapists, occupational therapists, or psychologists. Assistants to these staff members are often available. This kind of day care service may be offered at hospitals ("day hospitals") or as part of independent care units. The patients mostly come from their own living accommodation but may also come from homes for the aged, or nursing homes.

**Transportation**

Should only include care related transports, i.e. transports that are needed because of the disability of the patient.

**Other**

Services that the patient is receiving and that don’t correspond to the above options must be specified. Examples include organized volunteer workers, hired and paid people who are not from the professional sector. The number of visits and hours spent for all these “other” services combined must be recorded.
B. FOLLOW UP QUESTIONNAIRE

Indicate on the case report form which visit week the RUD© Follow-Up Questionnaire was administered to the caregiver.

As the follow up questionnaire shares many questions with the baseline questionnaire see previous instructions for common details.

The recall in the follow-up questionnaire is 30 days for caregiver time, and “since last study visit” for all other items.

B1. CAREGIVER

B1.1. Description of Primary Caregiver
This part should be filled in irrespective of whether there was a change since last visit.

B1.2. Caregiver Time
Note that in this section (caregiver time), the time frame is still the last 30 days. In the other follow-up questions, the time frame is “since the last study visit”.

B1.3. Caregiver Work Status
Since changes from baseline (and between the follow-ups) are of interest it is important for the investigator to look at the previous registration. Regarding caregivers, the focus is on the changes of work time and work situation due to care responsibilities.

B1.3.1. Working for pay
Note that the question focuses on paid work during part or the whole period. If the caregiver has changed jobs or working time or gets paid for care, all this is considered as paid work. Also note that even if the caregiver was on short term sick-leave (< 1 month) at baseline or last study visit, then he/she was registered as working at that time.

B1.3.2. Stopped working
Caregivers on short term sick-leave (< 1 month) at the visit are regarded as working for pay (option 2), while long term sick-leaves (> 1 month) have stopped working (option 1). If the caregiver was on long-term sick-leave during period but has started to work again, register option 2.

B1.3.3. Change in job or working situation
This includes new jobs but also changes in working time. If a caregiver has started to get paid for the care of the demented, it also means a changed working situation.

B1.4. Caregiver’s resource utilization
Whole section: same instructions as for the baseline questionnaire, just note that the time frame is since the last scheduled study visit.
B2. PATIENT

All resource utilization data reported in section B2 of the Follow-Up Questionnaire is for the period that has elapsed between two subsequently scheduled visits, (e.g. in the case of the first Follow-Up Questionnaire, for the period between the administration of the Baseline Questionnaire and the administration of this first Follow-Up Questionnaire).

B2.1. Patient Living Accommodation
See baseline questionnaire instructions. The time frame is since last scheduled visit in the study.

B2.1.1. Permanent Living Accommodation
In the case where several changes in permanent living accommodations occur between visits, consider them as temporary living accommodations and report them in B2.1.5. Consider the current living accommodation as being permanent.

B2.1.4. Reason for Change in Living Accommodation
The first four options deal with worsening of the patient and/or caregiver’s cognitive or functional abilities while options 5-8 describe improvements in these areas. There is a risk of overlap between these alternatives, but try to choose the single most relevant option.

B2.2. Patient Health Care Resource Utilization
See baseline questionnaire instructions. The time frame is since last scheduled visit in the study.