



DELIVERABLE

D4.3 – Analysis of improved quality of life of involved users and carers – first version

(accompanying report)

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D4.3 – Analysis of improved quality of life of involved users and carers – first version		
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx		Page: 1 of 45



1. Revision history and statement of originality

1.1. Revision history

Rev	Date	Author	Organization	Description
0.1	09-03-2016	Valentina Conotter	SOCIALIT	ToC,
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0.2	10-04-2016	Valentina Conotter	SOCIALIT	Introduction, Groups, Questionnaires
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0.6	27-06-2016	Maurizio Gianordoli	SOCIALIT	revision
1.0	28-06-2016	Giuseppe Conti	TRILOGIS	Final review

1.2. Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

2. List of references

Number	Full Reference
[1]	www.interrai.org
[2]	http://bibliography.interrai.org
[3]	Morris JN, Fries BE, Mehr DR, Hawes C, Philips C, Mor V, Lipsitz L. (1994) MDS Cognitive Performance Scale. <i>Journal of Gerontology: Medical Sciences</i> 49 (4): M174-M182.
[4]	Burrows A, Morris JN, Simon S, Hirdes JP, Phillips C. (2000) Development of a Minimum Data Set-based Depression Rating Scale for Use in Nursing Homes. <i>Age and Ageing</i> 29(2): 165-172.
[5]	Morris JN, Fries BE, Morris SA. (1999) Scaling ADLs within the MDS. <i>Journals of Gerontology: Medical Sciences</i> 54(11):M546-M553.
[6]	Hirdes JP, Poss JW, Curtin-Telegdi N. 2008. The Method for Assigning Priority Levels (MAPLe): A New Decision-Support System for Allocating Home Care Resources. <i>BMC Medical Informatics and Decision Making</i> 6: 9.
[7]	Rebecca Logsdon, Quality of Life-AD, 1996. Available at: http://www.dementia-assessment.com.au/quality/qol_handout_guidelines_scale.pdf
[8]	J.M. Glozman et al., Scale of Quality of Life of Caregivers (SQLC), Springer-Verlag 1998, <i>J. Neurol</i> 245: S39-S41
[9]	L. Yardley, et al., Development and initial validation of the Falls Efficacy Scale International (FES-I), <i>Age Ageing</i> , 34 (6) (2005), pp. 614-619

3. Table of Acronyms

Acronym	Description
AD	<i>Alzheimer Disease</i>
ADL	<i>Activities of Daily Living</i>
AL	<i>Assisted Living</i>
CAP	<i>Clinical Assessment Protocol</i>
CHA	<i>Community Health Assessment</i>
CI	<i>Cognitive Impairment</i>
CPS	<i>Cognitive Performance Scale</i>
DOA	<i>Description of Action</i>
FCG	<i>Formal Care Giver</i>
FES-I	<i>Fall Efficiency Scale-International</i>
HC	<i>Home Care</i>
HL	<i>Health Level Seven International</i>
IADL	<i>Instrumental Activities of Daily Living</i>
IADLC	<i>Instrumental Activities of Daily Living Capacity</i>
IADLP	<i>Instrumental Activities of Daily Living Performance</i>
ICG	<i>Informal Care Giver</i>
LTCF	<i>Long-Term Care Facilities Assessment System</i>
MAPLE	<i>Method for Assigning Priority Levels</i>
MDS	<i>Minimum Data Set</i>
MMCI	<i>Mild and Moderate Cognitive Impairment</i>
NCD	<i>Neuro Cognitive Disease</i>
PE	<i>Primary End-users</i>
QOL	<i>Quality of Life</i>
RUG	<i>Resource Utilization Group</i>

D4.3 – Analysis of improved quality of life of involved users and carers – first version

File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx

Page: 4 of 45



SQLC	<i>Scale of Quality of Life of Caregivers</i>
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4. Executive Abstract

One of the main goals of the UNCAP project is to offer a sensitive bundle of ICT tools to aid individuals, families and carers in managing their specific needs. UNCAP specifically aims at addressing the needs of ageing people with Cognitive Impairment (CI), and dementia. Enhancing the well-being of people with these conditions is a complex and evolving task. UNCAP fosters a modern non-pharmacological approach as an appropriate initial strategy in the support and care of individuals with CI. UNCAP is designed to assist the individual in maintaining dignity and independence and generally improving users' quality of life (QOL).

Offering the services would not be complete without evaluating the quality of life improvement and user satisfaction with a representative group of target user groups.

This document is devoted at describing all the aspects related to a complete evaluation of quality of life improvement, such as who are the participants, the inclusion/exclusion criteria, the indicators and the questionnaires that will be exploited for the QOL impact analysis.

It shall be noted that this document is very much related to D4.1, which describes the impact evaluation on the efficiency of the UNCAP technology.

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 6 of 45

5. Table of Content

1. Revision history and statement of originality	2
1.1. Revision history	2
1.2. Statement of originality	2
2. List of references	3
3. Table of Acronyms	4
4. Executive Abstract	6
5. Table of Content	7
6. Table of Figures	9
7. Table of Tables.....	10
8. The UNCAP study	11
8.1. Criteria for recruiting the test participants	12
8.1.1. Users definition and needs	12
8.1.2. Inclusion criteria.....	12
8.1.3. Exclusion criteria	14
9. QoL evaluation.....	14
9.1. Atl@nte	15
9.1.1. CPS – Cognitive Performance Scale	15
9.1.2. DRS – Depression Rating Scale.....	17
9.1.3. ADL – Activity Daily Living Self-performance Hierarchy Scale	17
9.1.4. IADL – Instrumental Activity Daily Living Performance scale (for HC).....	19
9.1.5. Behaviours patterns	19
9.1.6. Social functioning	20
9.1.7. MAPLE (for HC) – Methods for Assigning Priority Levels.....	20
9.2. Questionnaires	22
9.3. QOL-AD	22
9.4. SQLC	23
9.5. FES-I	23
9.6. General satisfaction of life	23
10. Reference Baseline extraction.....	24
10.1. Pilot in Athens	24
10.2. Pilot in Pergine	25
10.3. Pilot in Simleu Silvaniei.....	27
10.4. Pilot in Maribor	27
10.5. Pilot in Baia Sprie.....	27
10.6. Pilot in Città della Pieve.....	28
10.7. Pilot in Höhenkirchner.....	29
10.8. Pilot in Ovest Vicentino	29
10.9. Pilot in Skopje	30

D4.3 – Analysis of improved quality of life of involved users and carers – first version

File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx

Page: 7 of 45



10.10. Pilot in Tarzo	31
10.11. Pilot in Thessaloniki	32
11. Conclusions.....	33
12. Annex 1	34
12.1. QOL-AD	34
13. Annex 2	36
13.1. SQLC.....	36
14. Annex 3	41
14.1. FES-I.....	41
15. Annex 4	42
15.1. PE General satisfaction of life.....	42
15.2. ICG General satisfaction of life	43
15.3. FCG General satisfaction of life.....	44



6. Table of Figures

Figure 1 CPS evaluation steps	16
Figure 2 ADL evaluation steps.....	18
Figure 3 Example of the Behaviour pattern indicator in the INTERRAI PHP	19
Figure 4 Example of Social functioning indicator in the INTERRAI PHP	20
Figure 5 MAPLE evaluation procedure	21
Figure 6 Atl@nte scores distribution for the pilot in Athens.....	25
Figure 7 Atl@nte scores distribution for the pilot in Pergine	26
Figure 8 Atl@nte scores distribution for the pilot in Baia Sprie	28
Figure 9 Atl@nte scores distribution for the pilot in Città della Pieve	29
Figure 10 Atl@nte scores distribution for the pilot in Ovest Vicentino.....	30
Figure 11 Atl@nte scores distribution for the pilot in Skopje.....	31
Figure 12 Atl@nte scores distribution for the pilot in Tarzo	32



7. Table of Tables

Table 1 CPS scores	16
Table 2 ADL scores	19
Table 3 Tools employed for the QOL and satisfaction evaluation	22



8. The UNCAP study

Individuals with CI or dementia may have problems with their environment leading to stress, agitation and anxiety, and UNCAP can facilitate a reduction of these and other stressors. These interventions can be simple, such as redirecting and refocusing the individual, increasing social interaction, establishing regular habits eliminating sources of conflict and frustration, or more complex. Indeed, UNCAP also provides a range of sophisticated technologies assisting the individual to move safely around their home or general environment by using “transparent” monitoring tools and sensing aids (e.g. floor sensor matting). UNCAP also has the capability to monitor physical movements and clinical parameters, promoting exercise and training at emotional, physical and cognitive levels.

UNCAP provides solutions to support people with CI through a suite of physical and cognitive assessment tools, remote-monitoring features and through indoor/outdoor tracking capability.

In practice, UNCAP will deliver a product suite comprising of a low-cost Android-based unit, called the “UNCAP BOX” and a set of hardware and software compatible technology that can be tailored on user needs. The box will be connected to a standard digital television set with a USB port. This will allow collection of data from different indoor and outdoor localisation technologies including sensor flooring and camera-based detection systems and from sensors measuring vital parameters such as environmental temperature. The system makes the data available –via secure communication channels- to the “UNCAP CLOUD” for the access of authorized caregivers. The UNCAP BOX will also be used as the interface for individuals, caregivers and family members who will be able to communicate (also via video conference), exchange health data (via HL7 standard), access assessment of the individual’s conditions (through InterRAI™ assessment tools and methodology, Atl@nte suite) as well as to place emergency calls.

Most importantly, the UNCAP BOX will support interoperable communication, via KNX open protocol, with building automation systems and will deliver tailored services including individual lighting controls and “activity reminders”, for example flashing lights. The UNCAP BOX will be complemented by an App (UNCAP App also referred to as “UNCApp”) for smartphones or tablets. This will provide a convenient portable access to UNCAP services and allow access to selected UNCAP services in online and offline mode or from locations that are not compatible with the UNCAP infrastructure.

UNCAP modularity allows the customization of the bundle features according to the actual care setting and the users’ needs (both primary and secondary users’ needs). According to this, UNCAP will be tested for caring elderly people with Mild and Moderate Cognitive Impairment (MMCI) in two different settings:

- in long term care facilities as an additional care device;
- at the primary user home for providing home care services.

Eleven pilot sites in Europe will be involved in this clinical investigation, as described in the DoA. Each of the pilots will implement a specific set of UNCAP features chosen according to the specific application scenario, environment and users’ needs (please refer to D4.1 for further details).

The modularity and adaptability of UNCAP in different scenarios reflects the complexity of the clinical investigation to assess UNCAP usability and safety, users’

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 11 of 45

acceptance, satisfaction and quality of life. However, all pilot sites will share the same research questions, with a common set of primary and secondary outcomes and evaluation tools.

At all times, data sharing and analysis will respect the dignity, privacy and confidentiality of individual's personal information.

8.1. Criteria for recruiting the test participants

Since the study is designed to examine UNCAP technology as a non-pharmaceutical intervention within the subject home, at long term facilities or in community health centers, participant samples will include only people who live in their home or at long term facility and who have mild cognitive impairments to moderate cognitive decline (MMCI).

Detailed below are conditions regarding all user groups, inclusion and exclusion criteria and selection standards.

8.1.1. Users definition and needs

Primary end-user (PE): the old person (subject) with Mild and Moderate Cognitive Impairments who actually is using UNCAP or to which UNCAP technology is provided for. These people have difficulty in their everyday life, which comes due to cognitive problems and mild or moderate dementia. This group can directly benefits from the UNCAP technology and is expected to increase their quality of life.

Secondary end-users: persons directly being in contact with the primary end-user, such as formal and informal care persons, family members, friends. This group are expected to benefit from UNCAP technology directly when using the services and indirectly when the care needs of primary end users are reduced. Secondary end users will be grouped into two sub-categories according to the following:

- **Informal care-givers (ICG):** very often the closest family members are the direct care-givers and supporters in the daily care for the MMCI subjects. They would like to take care of their loved ones in a more efficient way, helping them to reduce their own burden and their own stress. They would also like to enjoy their life and maintain their social network.
- **Formal care-givers (FCG):** They want at any time to have overview of their MMCI subject conditions. Moreover, they need to provide them instructions, reminders and alarms.

8.1.2. Inclusion criteria

Based on the main user groups considered in the study, the UNCAP impact analysis will be evaluated on the following three test groups:

- PE test group - of primary end users – elderly people with cognitive problems or mild dementia, as well as normal elderly people
- ICG test group - of secondary end users – informal care givers. This includes close family members or family friends who take care of the senior

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 12 of 45



- FCG test group - of secondary end users – formal care givers. This test group includes home care personnel and specialised care giver personnel at long term care facilities.

PE group

The target primary end-user group will be elderly persons with Mild and Moderate Cognitive Impairments (MMCI) (2-3 CPS (Cognitive Performance Scale – see Section 9.1.1) stage and partially 4 stage, since some of 3 stage subjects, in 6-month duration of the test project periods, might progress to stage 4). The trial participants will be classified according to CPS score at enrolment.

Specific inclusion criteria for primary users include:

- Age above 60 years;
- Lives at home, or in a long term facility or is involved in a community health center.
- Diagnosed with Mild and Moderate Cognitive Impairments (MMCI) with a CPS score of 2-3 at enrolment.
- The MMCI diagnoses and stage is defined by a specialist (neurologist, geriatric specialist, etc.).
- Can self understand and give consent to participate in the project trial.
- Having a close relative or family-friend which is willing to help for the participation to the project trials as an informal caregiver is considered as preferential but not mandatory.

ICG group

ICGs will be considered as secondary users if they are:

- 18 years or older
- actively involved caregiver for the care recipient (provide at least on average of 5 hours of supervision or direct assistance per week)
- planning to remain in the area for the duration of the intervention and follow-up
- has performed the informal caregiver role for more than 6 months
- Not having dementia at any stage.

FCG group

FCGs will be considered accordingly to their willingness to cooperate. Once the potential FCG are identified, they will be contacted by one of the researchers (e.g. pilot responsible) who will further explain the project and answer any questions they may have. Formal caregivers will also be asked to identify the care giving situation from their (professional) point of view regarding ICG status, EP status and care giving situation. FCG will complete a screening tool to determine their occupational status and role in the care team. Formal caregivers are encouraged to participate in the

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 13 of 45

home visit of EP to assess the situation, setting and possible solutions. They will be asked for general satisfaction and specific satisfaction about UNCAP system features. Moreover they will be asked to provide data for addressing efficiency of the care system in respect to the primary user at both the enrolment and discharge time.

8.1.3. Exclusion criteria

The following exclusion criteria have been identified for the primary end user.

Those subjects meeting the following conditions will be excluded from the study.

- Mild neurocognitive disorder due to:
 - Drug abuse due to the presence of comorbidities with Personality Disorder not compatible with this study
 - HIV infection, since medical complications are not manageable
 - Nutrition deficiencies
- Individuals with depressive symptoms due to the presence of (minor/major) progressive deterioration;
- Participants whose dementia is reversible (nutrition deficiencies)
- Presence of psychiatric comorbidity;
- Presence of behavioural disorders (difficult research management);
- Individuals with severe functional or sensory impairment (e.g. visual impairment or certain physical disabilities), that could jeopardize the use of technological devices tested in the study;
- Individuals enrolled in a pilot study whose condition shows a rapid decline towards more severe forms of cognitive diseases or other conditions that result in an inability to use the technological devices tested in the study.
- Life expectancy <1 year
 - Due to matters related to budget limitations and costs per pilot, secondary exclusion criteria for the subjects of the test group will be:
- Participants living at home who do not have Internet access or for whom there is no possibly to provide such.
- Participants living in big homes (due to the limitation to buy and install many sensors in their homes)

9. QoL evaluation

The study aims at assessing improvements in the quality of life of users and the general satisfaction of the target groups.

In order to measure it the main variables that will be taken into account, as described in Section 9 are:

- Atl@nte indicators, such as Cognitive Performance Scale (CPS), Depression Rating Scale (DRS), Activity Daily Living Self-performance Hierarchy Scale (ADL), Instrumental Activity Daily Living Difficulty scale (IADL), Bahviours

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 14 of 45



patterns, Social functioning, Methods for Assigning Priority Levels (MAPLE, for HC).

- Ad-hoc questionnaires for measuring the QOL of the target users, such as QOL-AD (Quality of Life – Alzheimer Disease) for PEs, SQLC (Scale of Quality of Life of CareGivers) for ICGs, FES-I (Fall Efficiency Scale - International) of PEs.
- Ad-hoc questionnaires for measuring the general satisfaction of the target group.

In the following Sections all the tools for measuring the impact on the QOL of the target groups are detailed.

9.1. Atl@nte

As described in D1.5, e is a web-native solution supporting the definition of the care service path, which integrates multi-criteria assessment tools necessary for the collection of important information related to user's physical, cognitive and social conditions. The Atl@nte system is one of the few products in Europe that has been licensed for the use of the InterRAI tools for multidimensional assessment. Specifically, InterRAI provides a variety of internationally acknowledged instruments, each designed for a particular care setting (e.g., home and residential settings, daily centres, etc.), that use common measures so to allow clinicians and providers to guarantee a smooth continuity of care and to integrate clinical, psychological and cognitive supports for each individual. Some of these measures, all extracted from the Personal Health Profile of INTERRAI (see D1.5 as a reference) have been selected by the Ethical Committee as valuable indicators for the UNCAP impact analysis, as reported in the following.

Please also note that the INTERRAI evaluations will be carried out at least every three months during all the UNCAP clinical investigation.

9.1.1. CPS – Cognitive Performance Scale

The Cognitive Performance Scale (CPS) combines information on memory impairment, level of consciousness, and executive function, with scores ranging from 0 (intact) to 6 (very severe impairment). Figure 1 depicts the procedures and the information taken into account within the InterRAI algorithm for calculating the CPS scale [3].

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 15 of 45

Cognitive Performance Scale

Impairment Count (number of the following):

- Decision Making: Not Independent (1, 2, 3)
- Understood: Not Independent (1, 2, 3, 4)
- Short-Term Memory: Not OK (1)

Severe Impairment Count (number of the following):

- Decision Making: Moderate Impairment (3)
- Understood: Sometimes/Never (3, 4)

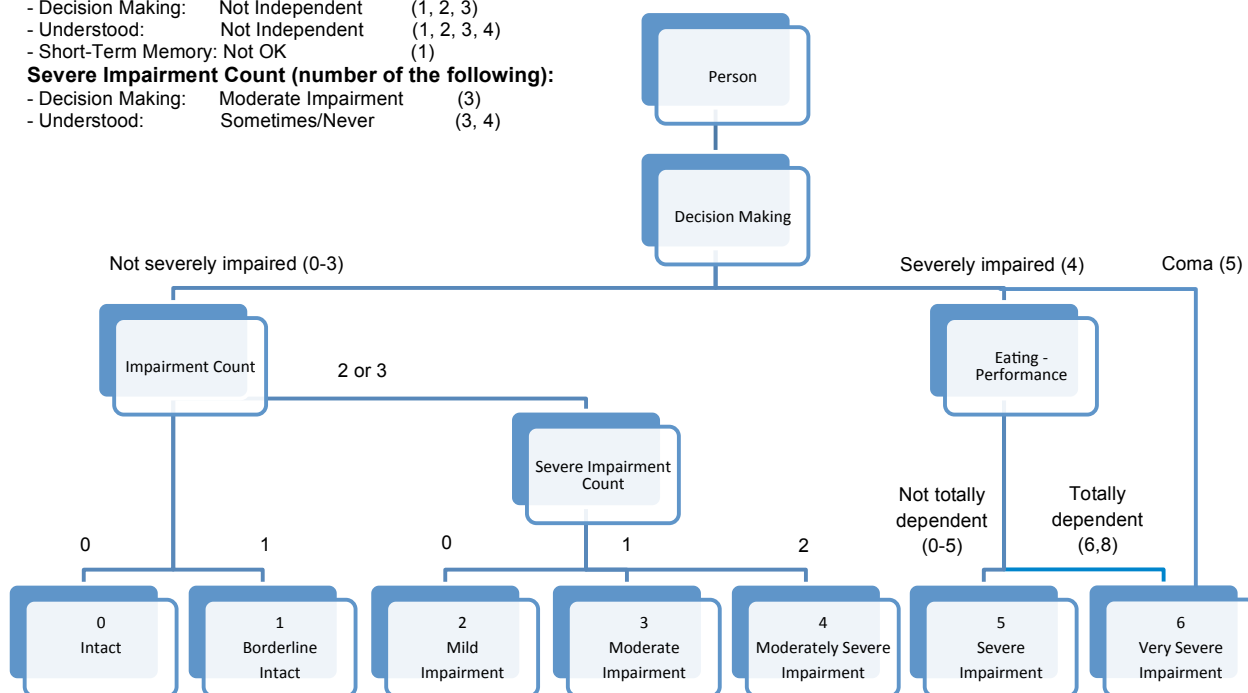


Figure 1 CPS evaluation steps

Scores are based on skills for daily decision-making, making self understood, and short-term memory recall. "Eating impairment" differentiates a score of 5 or 6. Higher scores indicate a greater degree of cognitive impairment. The CPS has been shown to be highly correlated with the MMSE in a number of validation studies, as shown in Table 1, and will be evaluated to measure the evolution of the cognitive functionalities of the end users.

Score	Description	Equivalent Average MMSE
0	Intact	25
1	Borderline intact	22
2	Mild impairment	19
3	Moderate impairment	15
4	Moderate/severe impairment	7
5	Severe impairment	5
6	Very severe impairment	1

Table 1 CPS scores



9.1.2. DRS – Depression Rating Scale

The Depression Rating Scale (DRS) is used as a clinical screen for depression. Validation studies were based on a comparison of the DRS with the Hamilton Depression Rating Scale and the Cornell Scale for Depression. Compared to DSM-IV major or minor depression diagnoses, the DRS was 91% sensitive and 69% specific at a cut-point score of 3 out of 7 [4].

Scores range from 0 to 14. The DRS is based on 7 MDS-HC items: negative statements, persistent anger, expressions of unrealistic fears, repetitive health complaints, repetitive anxious complaints, sad or worried facial expression, and tearfulness. A score of 3 or greater suggests possible depression.

9.1.3. ADL – Activity Daily Living Self-performance Hierarchy Scale

The ADL Hierarchy Scale groups activities of daily living according to the stage of the disablement process in which they occur. Early loss ADLs (for example, dressing) are assigned lower scores than late loss ADLs (for example, eating). Figure 2 shows the evaluation procedure for the computation of the ADL Hierarchy Scale [5].

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 17 of 45

ADL Hierarchy Scale

The four items used to score the scale (0-6) are:

- **Personal hygiene**
- **Toilet use**
- **Locomotion**
- **Eating**

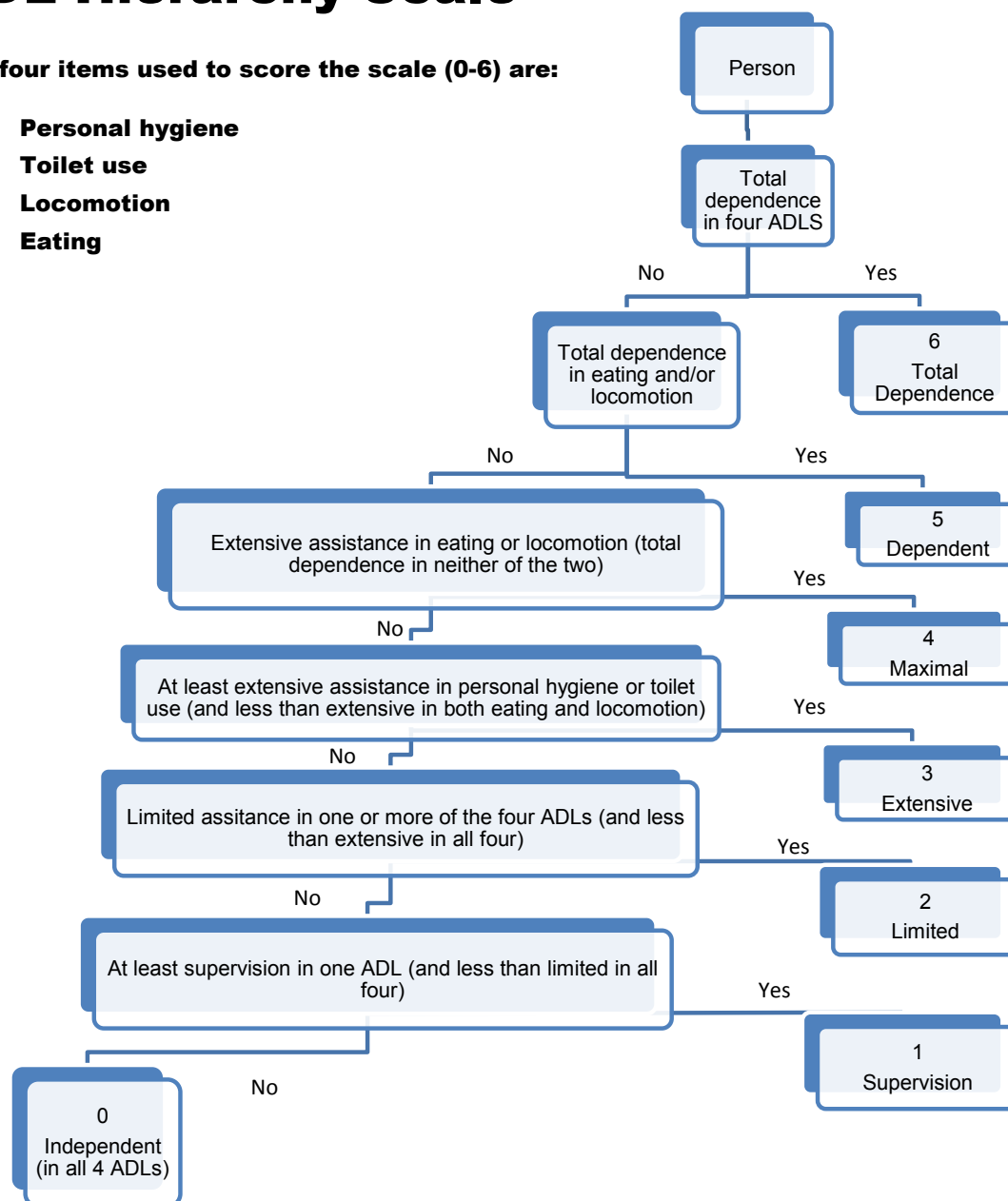


Figure 2 ADL evaluation steps

The ADL Hierarchy ranges from 0 (no impairment) to 6 (total dependence). As shown in the ADL Hierarchy measures activities of daily living performance according to early, middle, and late stages of loss using 4 ADLS: personal hygiene, toilet use, locomotion, & eating. This scale will be used for measuring the improving in the physical conditions.

Score	Description
0	Independent – all 4 ADLs either independent or setup help only
1	Supervision required – 1 or more ADLs require supervision
2	Limited impairment – 1 or more ADLs require limited assistance
3	Extensive assistance required (I) – no more than limited assistance in eating or locomotion but toilet use or personal hygiene require extensive assistance or more
4	Extensive assistance required (II) – no more than maximal assistance in eating or locomotion but toilet use or personal hygiene are totally dependent or did not occur
5	Dependent – eating or locomotion is totally dependent or did not occur but at least one of 4 ADLs are less impaired
6	Total dependence – 4 ADLs are either totally dependent or did not occur

Table 2 ADL scores

9.1.4. IADL – Instrumental Activity Daily Living Performance scale (for HC)

The IADL Performance Scale was developed to provide a simple method to summarize the multiple measures of higher-level functioning represented by the instrumental activities of daily living.

The IADL Performance Scale summarizes the 8 performance items - what the individual actually does. Higher scores indicate less performance.

The scale runs from 0 to 48.

9.1.5. Behaviours patterns

These INTERRAI outcomes describe the presence of behaviour disorders such as Wandering, Verbal abuse, Physical abuse, Socially inappropriate or disruptive behaviour, resists care.

Behaviour Patterns

Wandering	Not present
Verbal abuse	Not present
Physical abuse	Not present
Socially inappropriate or disruptive behavior	Not present
Resists care	Not present

Figure 3 Example of the Behaviour pattern indicator in the INTERRAI PHP



9.1.6. Social functioning

This INTERRAI outcome describe the social behaviour of the elderly, indicating her/his attitude in participating in social activities of long-standing interest.

Social Functioning

Participation in social activities of long-standing interest

Figure 4 Example of Social functioning indicator in the INTERRAI PHP

9.1.7. MAPLE (for HC) – Methods for Assigning Priority Levels

MAPLe differentiates service seekers/clients into five priority levels, based on their risk of adverse outcomes. Clients in the lowest priority level have no major functional, cognitive, behavioural, or environmental problems and are considered self-reliant. The highest priority level is based on presence of ADL impairment, cognitive impairment, wandering, behaviour problems, and the InterRAI nursing home risk CAP. Research has demonstrated that the five priority levels are predictive of risk: Individuals in the highest priority level are nearly nine times more likely to be admitted to a long- term care facility than are the lowest priority clients. MAPLe also predicts caregiver stress. Figure 5 shows the evaluation procedure for the calculus of the ADL Hierarchy Scale [6].

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 20 of 45

MAPLe

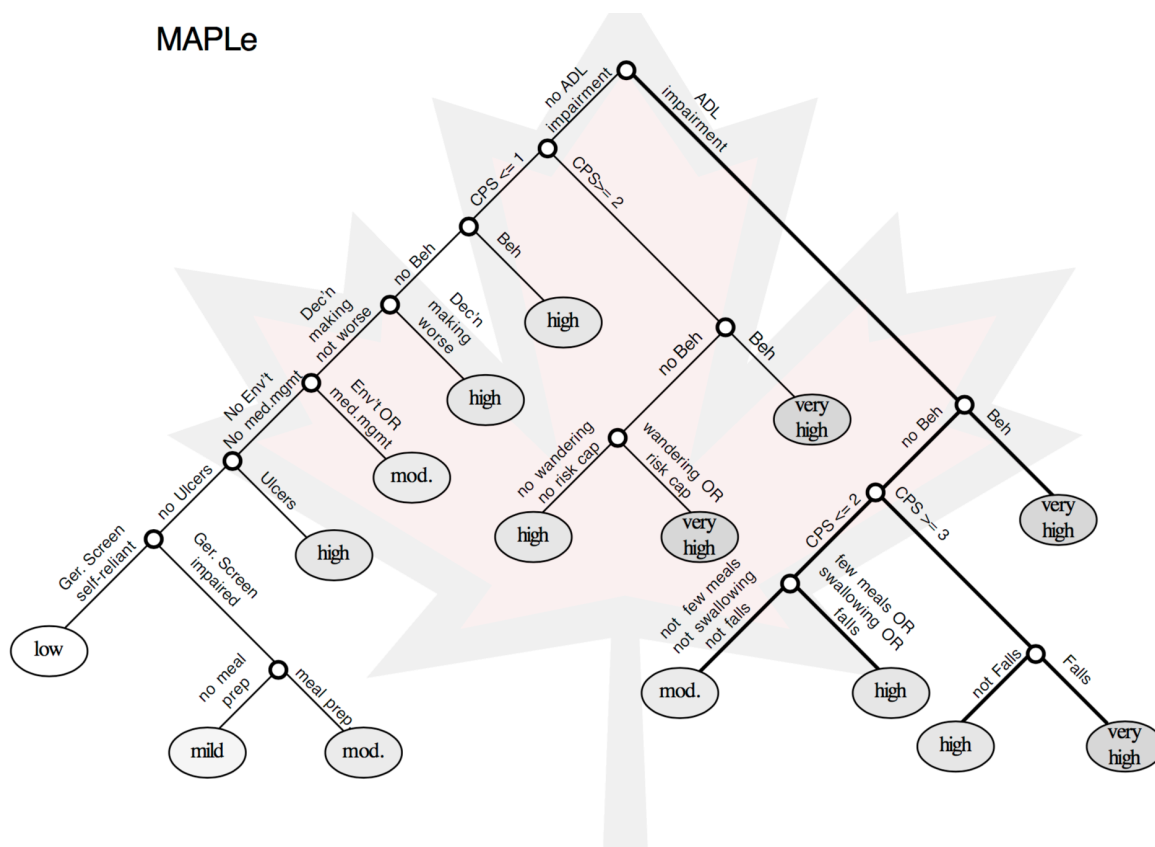


Figure 5 MAPLe evaluation procedure

Scores range from low to very high. MAPLe is calculated from HC items known to be predictive of facility admission, caregiver stress, or a feeling that the client would be better off elsewhere.

All the described indicators will be considered for the QOL evaluation within those pilots employing the LTCF and HC InterRAI tool (except MAPLe which is used only for HC). Please refer to D1.5 for the association of pilots and InterRAI instruments. For the only pilot in Thessaloniki employing CHA-AL instrument, the CPS and the DRS scale will be considered, as described above. Besides these two indicators, three specifically designed scales will be exploited:

- **IADLP** (*Instrumental Activities of Daily Living Performance*): measure for the performance of IADL. [scores from 0 to 48]
- **IADLC** (*Instrumental Activities of Daily Living Capacity*): measure for the capacity of IADL. [scores from 0 to 48]
- **COMM**: measure for the capacity of communication (express needs and comprehension)[scores from 0 to 48]

9.2. Questionnaires

For assessing the QOL and the general satisfaction of the target users, some standard and ad-hoc compiled questionnaires will be used. Table 3 Tools employed for the QOL and satisfaction evaluation

summarizes the employed questionnaires, detailing the expected time needed for compilation. More details on these instruments are given in the following sections.

It is important to underline that in order to make accurate objective comparisons, the first round of evaluations for QOL analysis will be conducted right at the beginning of the clinical trial, while a second round will be performed after the study has been concluded. As far as the general satisfaction is considered, a unique round of evaluation will be conducted at the end of the clinical study. Please note that the methodology for conducting the evaluations with the described questionnaires has been described in D4.1.

Moreover, whenever needed, the pilot, with the support of their supporting technical partner, will conduct the translation of the questionnaires, under their responsibility. All results will be however presented in English.

Evaluation aspect	Assessment tool	End user involved	Expected time for compilation	Assessment method
QOL of PE	QOL-AD	PE	10 minutes	Questionnaire administered with support
QOL di ICG	SQLC	ICG	10 minutes	Self-administered questionnaire
General Satisfaction	Ad-hoc questionnaires for general satisfaction	PE, ICG, FCG	5 minutes	Self-administered questionnaire

Table 3 Tools employed for the QOL and satisfaction evaluation

9.3. QOL-AD

QOL-AD includes patient and ICG report of patient's quality of life, it is reliable and valid for individuals with CPS lower than 3. It is 13-item questionnaire with 4-pt responses which takes usually 10 minutes. Answers are structured on a four-choice scale and items are rated according to *current* status. Patients complete the QOL-AD in an interview format and ICG complete a questionnaire, both taking less than fifteen minutes. Answers are recorded and PE response scores are doubled, added to ICG scores and the total is divided by three to give more weight to the primary subjective evaluation; higher scores indicating higher reported quality of life. Interviewers will use a set of explicit instructions in order to avoid influencing participant responses. Participants will also follow along on their own copy of the measurement and can either respond verbally or mark their own response [7]. If a PE is unable to comprehend/respond to more than two items, the interview will be discontinued and that PE will be considered "unable or unwilling to complete the assessment." The participant version of the instrument could be seen in Annex 1.



9.4. SQLC

Another, more recent and advanced assessing tool for measuring QOL of informal caregivers, specifically designed for carers of patients with cognitive problems, is the Scale of Quality of Life of Care-Givers (SQLC) [8]. It has been developed to analyse the quality of life of parkinsonian patients' caregivers and additionally some factors determining their social disadaptation. It is a comprehensive questionnaire covering the persons' activities from different aspects: professional, family related, social and others. It evaluates both qualitatively and quantitatively the principal levels of the subject's activities: (a) professional activity of the care-giver, (b) social and leisure activities, (c) responsibilities of the care-giver to help the patient in everyday living. It is a total of 16 questions, divided in three sections. The participant version of the instrument could be seen in Annex 2.

9.5. FES-I

Fall Efficacy Scale - International (FES-I) is a questionnaire that assesses fear of falling (FOF). Fear of falling has been defined as an ongoing concern about falling, which ultimately limits the performance of activities of daily living. The 16-item FES-I was developed by the Prevention of Falls Network Europe group (ProFaNE) to augment content covered by the original 10-item Fall Efficacy Scale (FES); the social dimension of FOF was added [9]. The participant version of the instrument could be seen in Annex 3.

9.6. General satisfaction of life

Ad-hoc questionnaires have been specifically designed, with the help of the Ethical and Medical Committee, in order to assess the general level of satisfaction of life for all the target users (PE, ICG, FCG). The participant version of the instrument could be seen in Annex 4.

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 23 of 45

10. Reference Baseline extraction

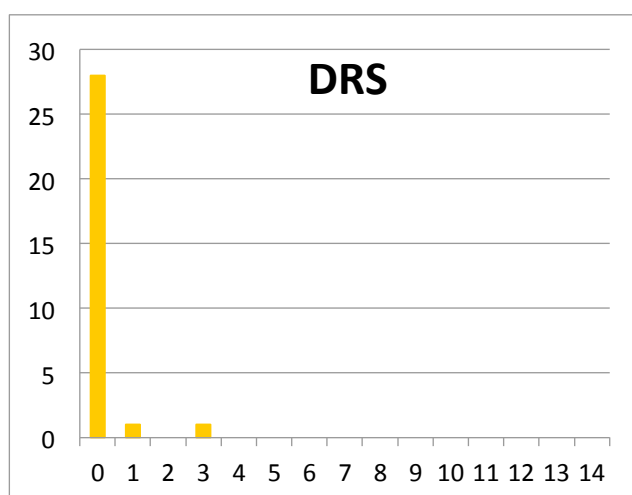
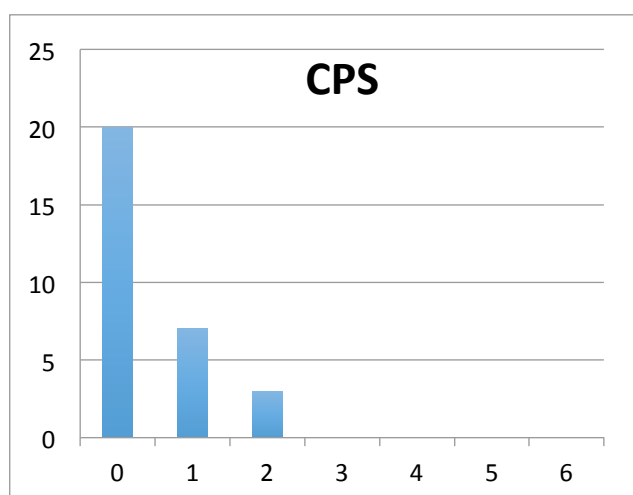
As described in D1.5, Within UNCAP, all the pilot sites have been provided with the Atl@nte system and the corresponding assessment instruments at M06. The pilot partners have been using them since then (12 months as for now) to extract key indicators regarding quality of life and other clinical or cognitive aspects of users, before the UNCAP system is introduced. This data represent a reference baseline for the second 12-month long assessment phase (starting at M18), done after UNCAP is deployed at the pilot sites. The assessments carried on before the introduction of UNCAP clearly depict the level of quality of life of patients and care givers in a “standard” health-care system, while the second assessment phase will include data collection from users both using and not using UNCAP technologies, so to provide a true benchmarking by comparing the evaluations results obtained by the two groups.

We report here some data extracted from the assessment performed by each pilot, which consist in a number of indicators, as described in Section 9.1, that create a statistically relevant and scientific grounding baseline for depicting a clear overall health status of the patients in the UNCAP pilots, thus drawing some guidelines for the definition of the inclusion/exclusion criteria for enrolment in the following UNCAP clinical trials.

10.1. Pilot in Athens

The pilot in Athens, Greece, is using the Home Care instrument and, up to now, there are 30 assessments performed in the system.

The following figures draw the distribution of the CPS, DRS, ADL and IADL scales for all the considered patients.



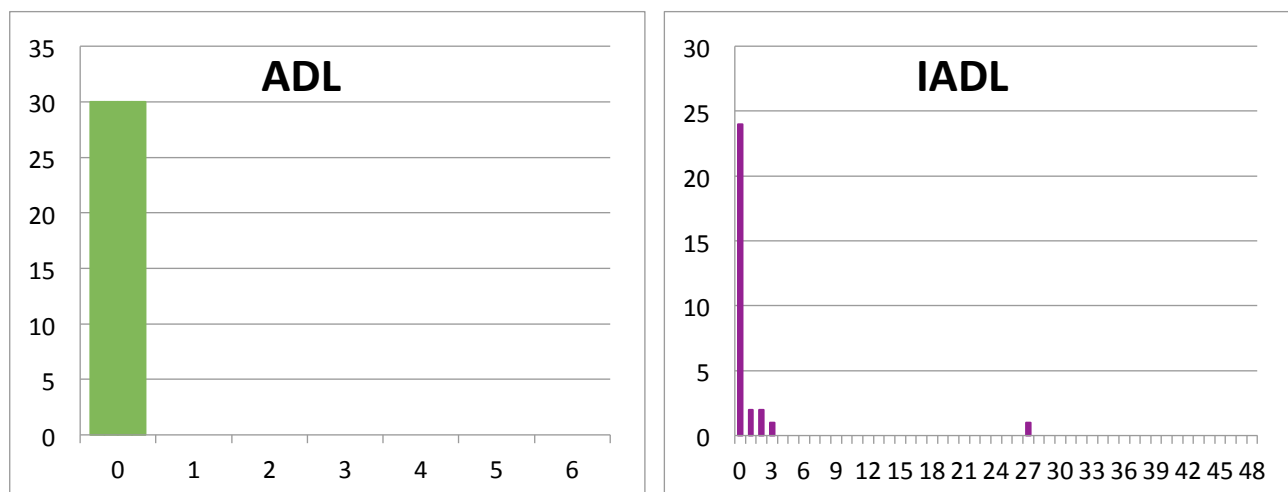


Figure 6 Atl@nte scores distribution for the pilot in Athens

From all the scores we notice that the pilot in Athens deals with elderly with good cognitive and physical conditions. Indeed, the MAPLE index reports on average a low score, as shown in Figure 7.

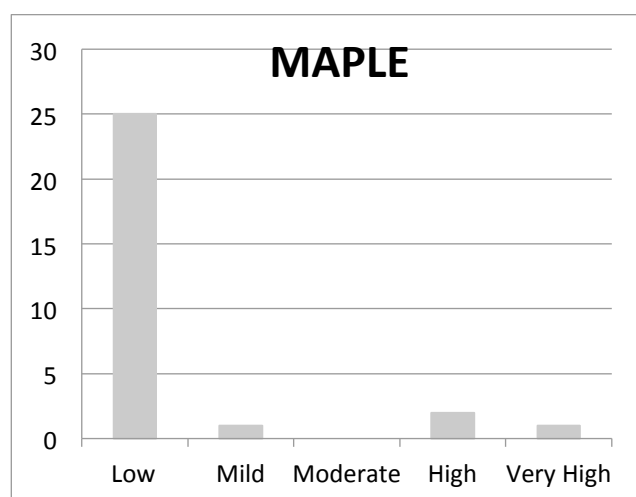


Figure 7 MAPLE score distribution for the pilot in Athens

10.2. Pilot in Pergine

The pilot in Pergine, Italy, is also using the Home Care instrument and, up to now, there are 25 assessments performed in the system.

The following figures draw the distribution of the CPS, DRS, ADL and IADL scales for all the considered patients.

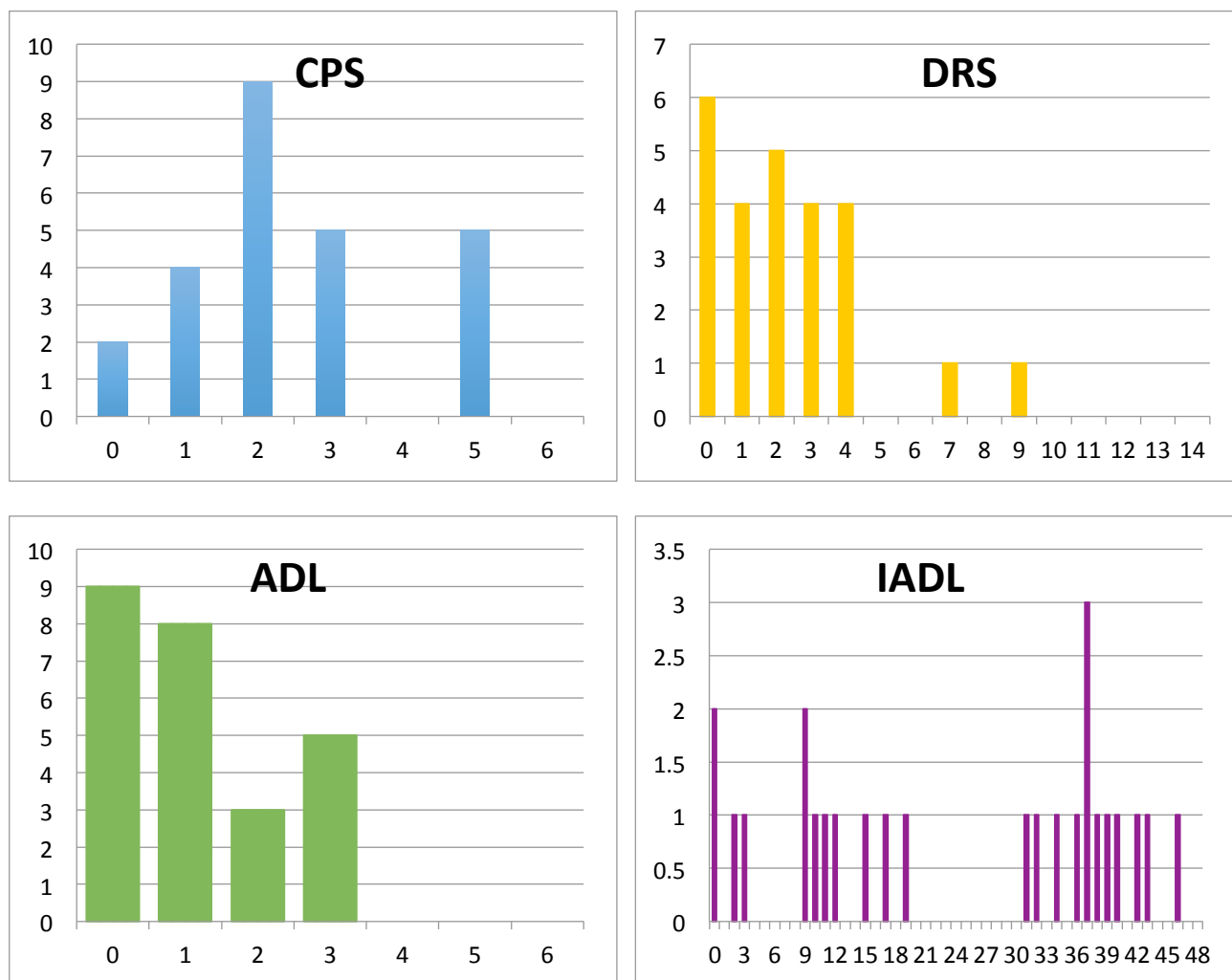


Figure 8 Atl@nte scores distribution for the pilot in Pergine

From the distributions, we may notice that the general health condition of the patients in Pergine ranges from low to moderate. Indeed, the MAPLE index reports on average a moderate to high score, as shown in Figure 9.

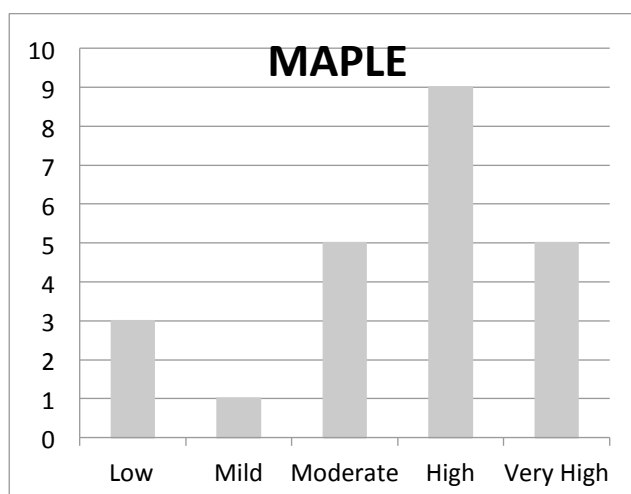


Figure 9 MAPLE score distribution for the pilot in Pergine

10.3. Pilot in Simleu Silvaniei

The pilot in Simleu Silvaniei, Romania, is also using the Home Care instrument and, up to now, there are 4 assessments performed in the system.

However, the pilot reported that 20 elderly have been involved in the project, but no InterRAI assessments have been provided for all of them. They are however currently fully supported to use the system for the clinical trial evaluation.

10.4. Pilot in Maribor

The pilot in Maribor, Slovenia, is using the Home Care (HC) instrument and, up to now, there are 22 assessments performed in the system.

These data confirms that the pilot is actively using the assessment tools. However, the inserted assessments are no complete and no output can be given by the InterRAI tools. The technical partners are fully supporting the pilot in performing correctly the task.

10.5. Pilot in Baia Sprie

The pilot in Baia Sprie, Romania, is using the Long Term Care Facilities (LTCF) instrument and, up to now, there are 20 assessments performed in the system.

The following figures draw the distribution of the CPS, DRS and ADL scales for all the considered patients.

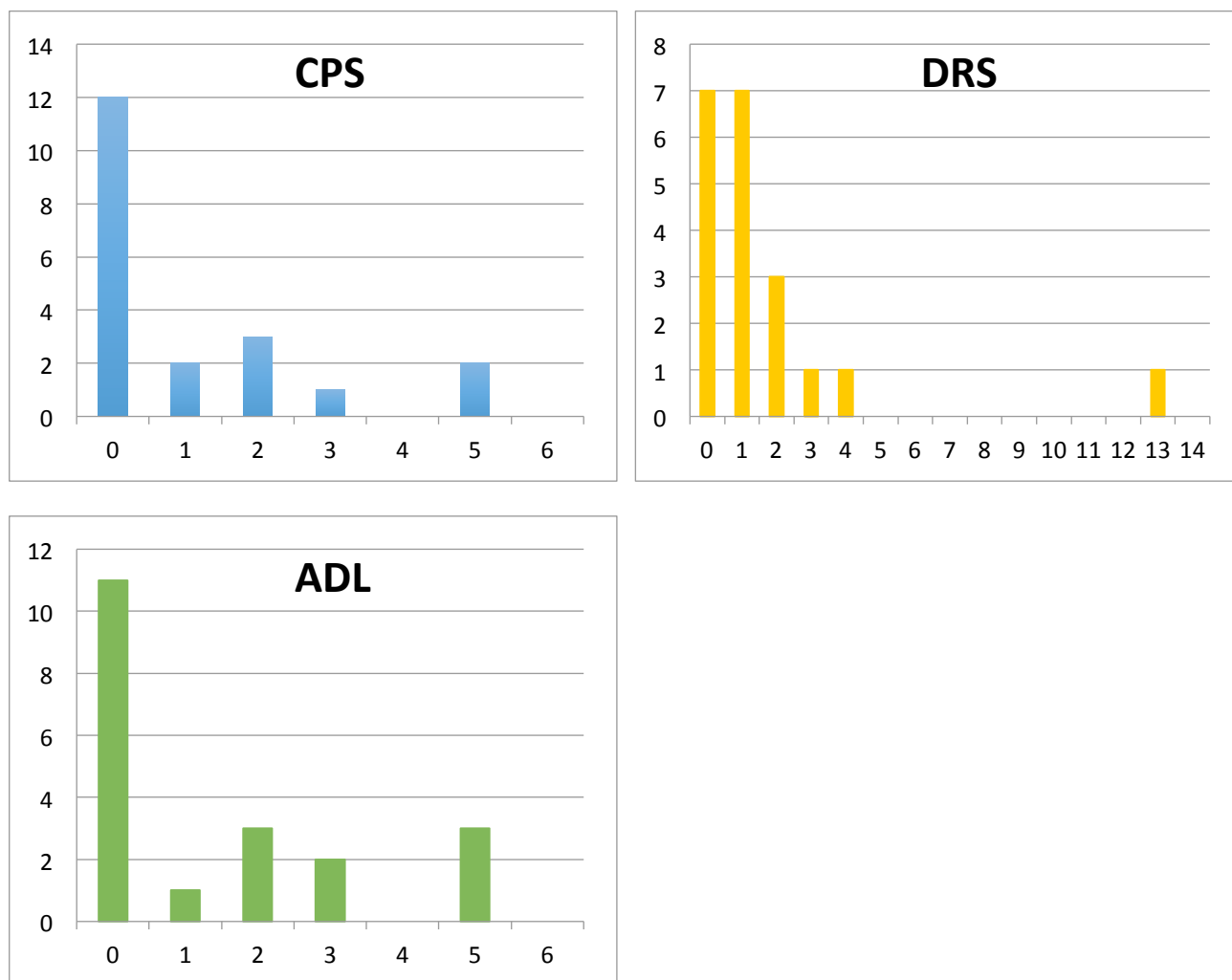


Figure 10 Atl@nte scores distribution for the pilot in Baia Sprie

From the distributions, we may notice that the general health condition of the patients in Baia Sprie is on average good (low cognitive and physical impairment).

10.6. Pilot in Città della Pieve

The pilot in Città della Pieve, Italy, is using the Long Term Care Facilities (LTCF) instrument and, up to now, there are 28 assessments performed in the system.

The following figures draw the distribution of the CPS, DRS and ADL scales for all the considered patients.

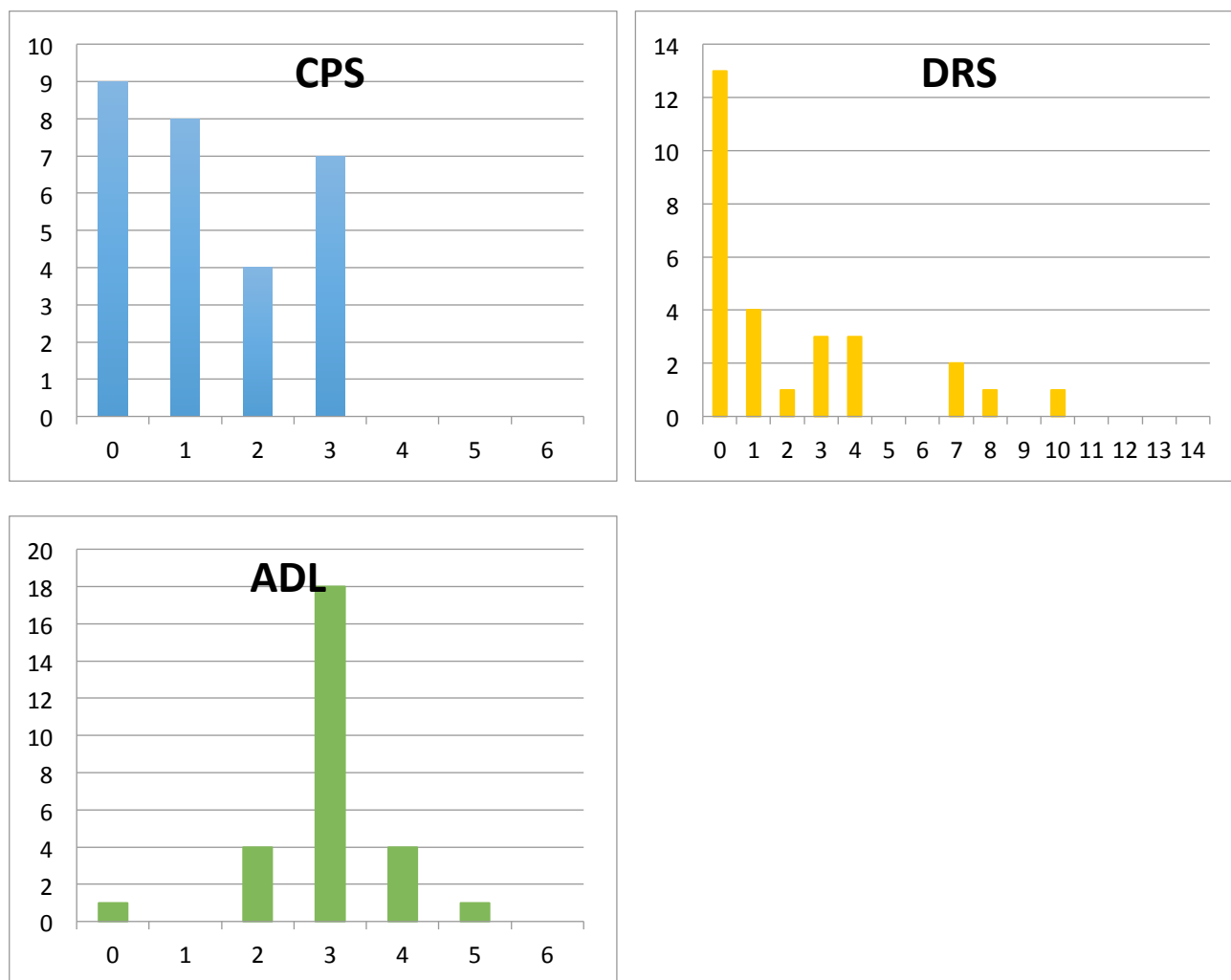


Figure 11 Atl@nte scores distribution for the pilot in Città della Pieve

From the distributions, we may notice that the patients in Città della Pieve present on average mild to moderate cognitive and physical impairment.

10.7. Pilot in Höhenkirchner

The pilot in Höhenkirchner, Germany, as reported in D3.3, “*is no collecting data with Atl@nte. The pilot’s responsible highlighted that for their specific needs this process is not needed and regarded as time consuming*”.

10.8. Pilot in Ovest Vicentino

The pilot in Ovest Vicentino, Italy, is using the Long Term Care Facilities (LTCF) instrument and, up to now, there are 88 assessments performed in the system.

The following figures draw the distribution of the CPS, DRS and ADL scales for all the considered patients.

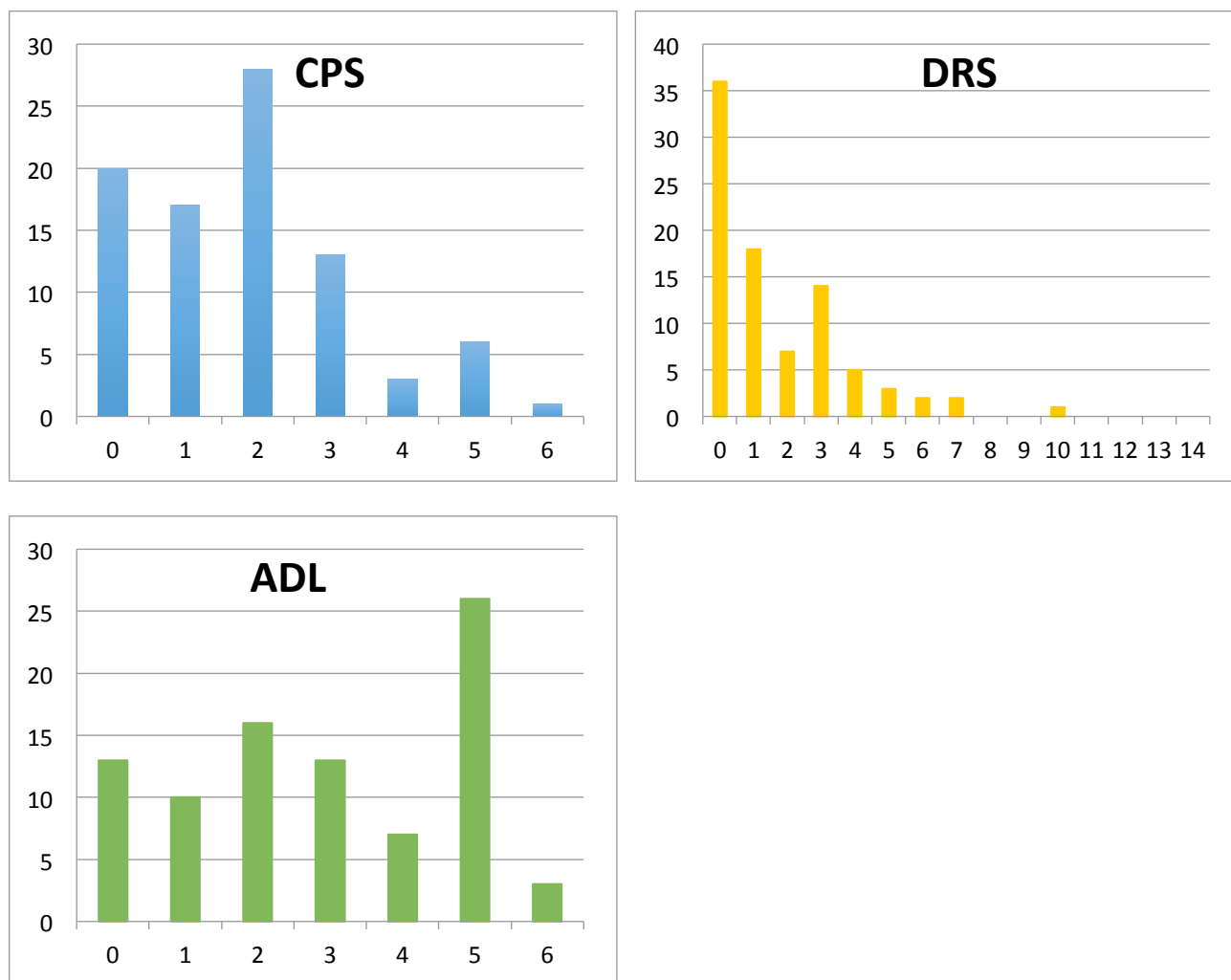


Figure 12 Atl@nte scores distribution for the pilot in Ovest Vicentino

From the distributions, we may notice that the patients in Ovest Vicentino present on average mild to moderate cognitive and physical impairment.

10.9. Pilot in Skopje

The pilot in Skopje, Macedonia, is using the Long Term Care Facilities (LTCF) instrument and, up to now, there are 46 assessments performed in the system.

The following figures draw the distribution of the CPS, DRS and ADL scales for all the considered patients.

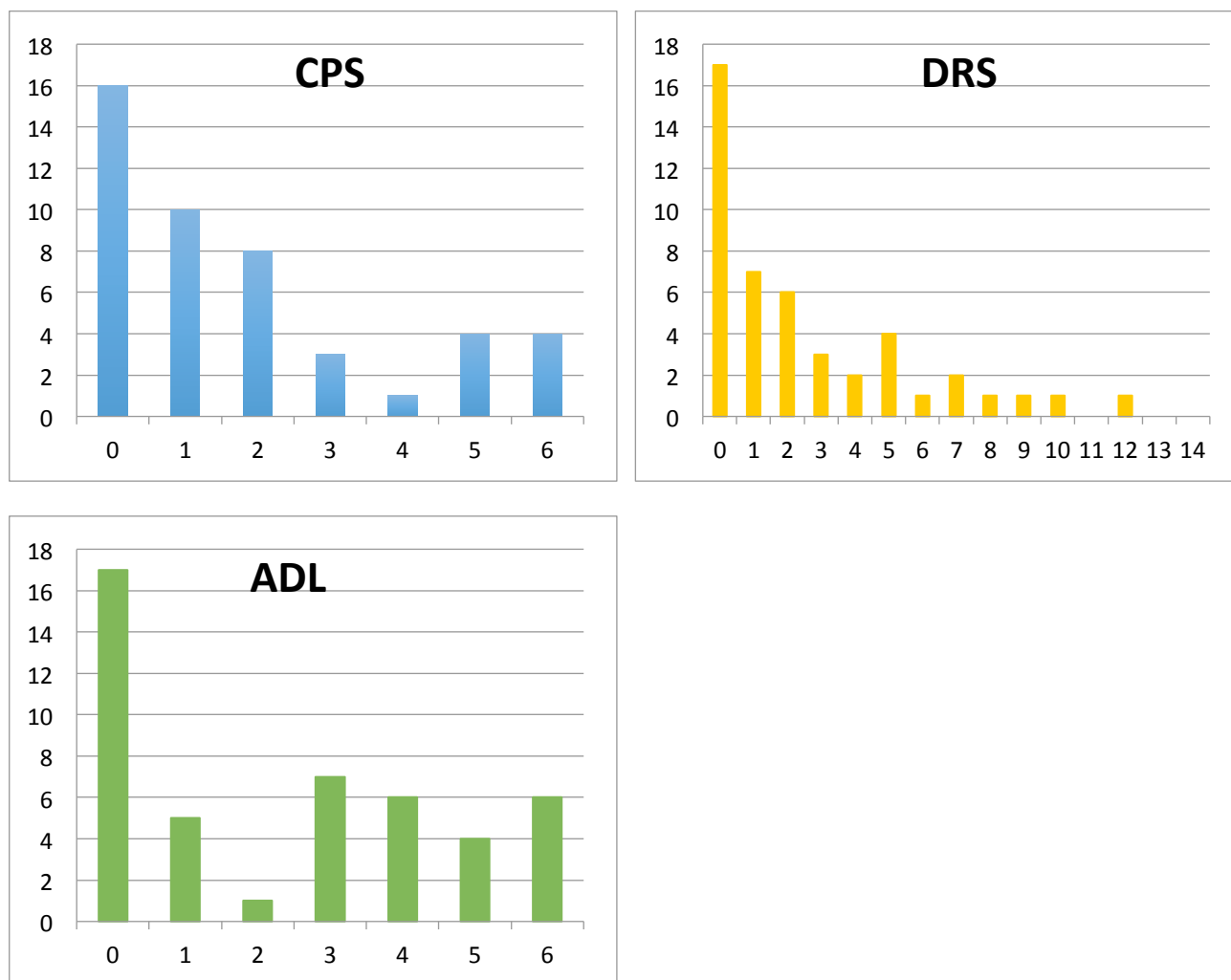


Figure 13 Atl@nte scores distribution for the pilot in Skopje

From the distributions, we may notice that the patients in Skopje present on average mild cognitive and physical impairment.

10.10. Pilot in Tarzo

The pilot in Tarzo, Italy, is using the Long Term Care Facilities (LTCF) instrument and, up to now, there are 90 assessments performed in the system.

The following figures draw the distribution of the CPS, DRS and ADL scales for all the considered patients.

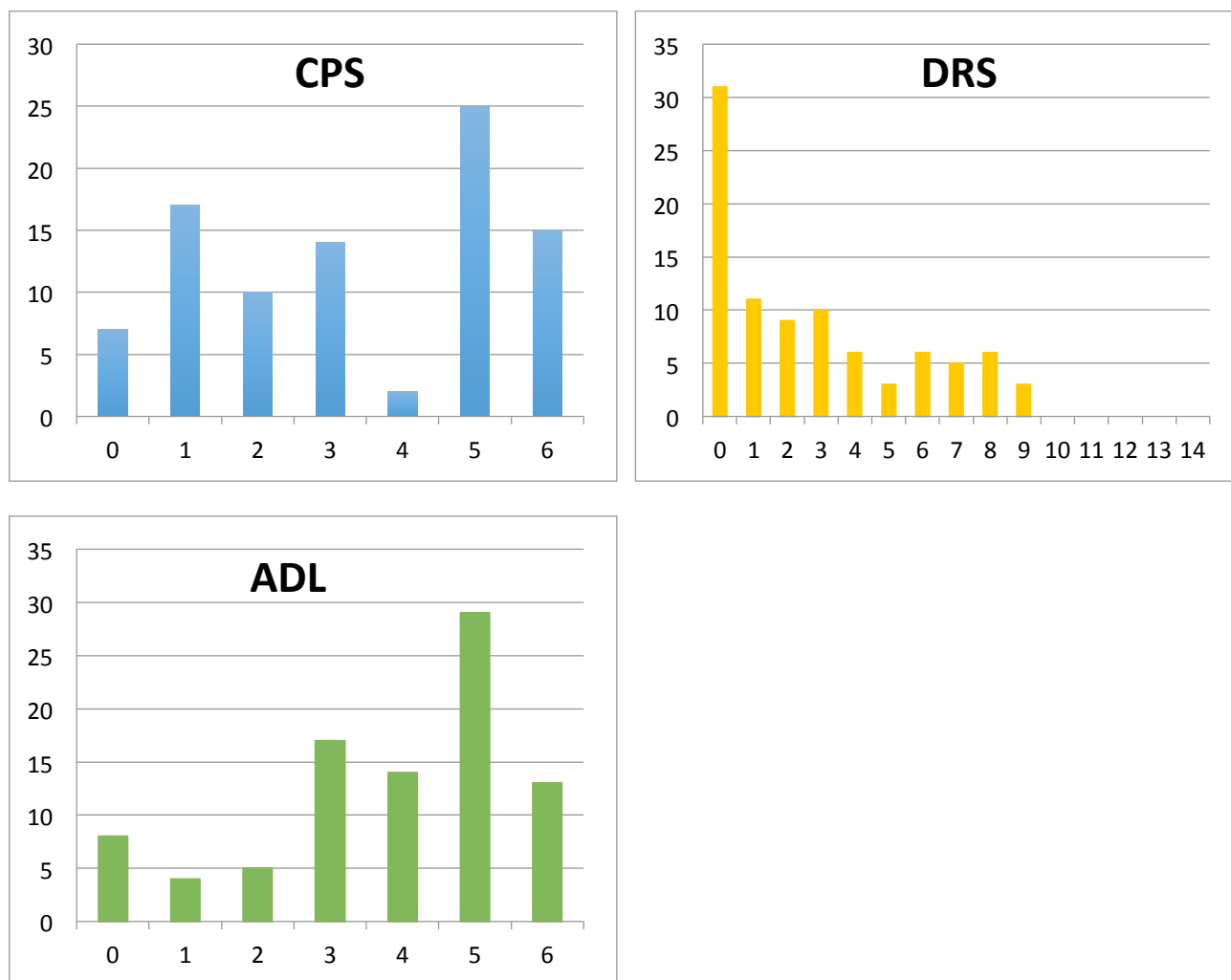


Figure 14 Atl@nte scores distribution for the pilot in Tarzo

From these distributions, we can note that the elderly people staying at the pilot in Tarzo are on average more cognitively and physically impaired with respect to the other pilots.

10.11. Pilot in Thessaloniki

The pilot in Thessaloniki, Greece, is using the Community Health Assessment (CHA) instrument and, up to now, there are 117 assessments performed in the system.

These data confirms that the pilot is actively using the assessment tools. However, due to a technical issue, no InterRAI scale can be reported now, but it is guaranteed that such information will be provided in the next deliverable concerning the clinical trial evaluation.



As already stated previously, the absence of baseline data for some of the pilots is due to the lack of completeness of the InterRAI evaluation. Specifically, InterRAI is an algorithm that provides its output only if all the needed input information are completed. If this is not the case, no output data can be calculated. In some of the pilots some problems occurred in the full completion of the evaluations, even if the Atl@nte system in general is up and running, and has been used, in all the pilot centers. All the supporting partners are currently providing all the needed help to complete such evaluations, helping the involved clinicians to retrieve all the needed clinical information to complete the assessments.

11. Conclusions

In this deliverable we described the assessment instruments that will be used for evaluating the impact of UNCAP on the quality of life of the involved users. Specifically, we described the target users as divided in primary end users, formal care givers and informal caregivers. The assessment instruments consist of both InterRAI indicators and ad-hoc questionnaires: the former will be extracted every 3 months during the clinical trial (pilots will perform the InterRAI assessment within the Atl@nte system), while the latter will be administered following the procedure described in D4.1.

Finally, a baseline of QOL indicators extracted from Atl@nte has been provided for each pilot, coming from a first 12-month assessment. These data create a statistically relevant and scientific grounding baseline for depicting a clear overall health status of the patients in the UNCAP pilots, thus drawing some guidelines for the definition of the inclusion/exclusion criteria for enrolment in the following UNCAP clinical trials.

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 33 of 45



12. Annex 1

12.1. QOL-AD

Beneficiary: Primary End User

Provider: IFC or FCG

To distribute at the enrolment period and at the end of the experimentation

Expected average time for the filling in: 10 minutes

The partner FBK is currently in the process of obtaining the needed licence for scientifically using this instrument.

QOL-AD				
Interviewer administer according to standard instructions. Circle responses.				
Physical health	POOR	FAIR	GOOD	EXCELLENT
Energy	POOR	FAIR	GOOD	EXCELLENT
Mood	POOR	FAIR	GOOD	EXCELLENT
Living situation	POOR	FAIR	GOOD	EXCELLENT
Memory	POOR	FAIR	GOOD	EXCELLENT
Family	POOR	FAIR	GOOD	EXCELLENT
Marriage	POOR	FAIR	GOOD	EXCELLENT
Friends	POOR	FAIR	GOOD	EXCELLENT
Self as a whole	POOR	FAIR	GOOD	EXCELLENT
Ability to do chores around the house	POOR	FAIR	GOOD	EXCELLENT
Ability to do things for fun	POOR	FAIR	GOOD	EXCELLENT



Money	POOR	FAIR	GOOD	EXCELLENT
Life as a whole	POOR	FAIR	GOOD	EXCELLENT

Instructions for interviewers are described, as in [7]:

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below. Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.

Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.

How do you feel about your energy level? Do you think it is poor, fair, good, or excellent? If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.

How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 35 of 45



How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?

How about your memory? Would you say it is poor, fair, good, or excellent?

How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent? If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.

How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent? Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. If there is no one appropriate, or the participant is unsure, score the item as missing. If the participant's rating is of their relationship with someone other than their spouse, note this and record the relationship in the comments section.

How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent? If the respondent answers that they have no friends, or all their friends have died, probe further. Do you have anyone you enjoy being with besides your family? Would you call that person a friend? If the respondent still says they have no friends, ask how do you feel about having no friends—poor, fair, good, or excellent?

How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?

How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?

How about your ability to do things for fun, that you enjoy? Would you say it's poor, fair, good, or excellent?

How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent? If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.

How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?

SCORING INSTRUCTIONS FOR THE QOL:

Points are assigned to each item as follows: poor=1, fair=2, good=3, excellent=4. The total score is the sum of all 13 items.

D4.3 – Analysis of improved quality of life of involved users and carers – first version	
File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx	Page: 36 of 45

13. Annex 2

13.1. SQLC

Beneficiary: Informal Care Giver

Provider: self-administered questionnaire

To distribute at the enrolment period and at the end of the experimentation

Expected average time for the filling in: 10-15 minutes

I. Professional activity

1. Have you continued at your former place of work after your relative fell ill?

Yes (5) No (0)

Full-time, for full working day	5	0
Part-time with incomplete working day	3	0
Had to start working (if hadn't worked before)	0	5
Didn't work before either	5	0

2. Do you manage to perform your duties while now being occupied with the patient's care? Yes (5) No (0)

As well as previously	5	0
With difficulty	3	0
Partly manage	1	0
Not at all	0	0

3. Did you change your work because of your relative's disease? Yes (0) No (4)

If yes, your job is now:

The same as previously	3	0
Close to previous type	2	0
In another branch	1	0
Changed the job for other reasons not related to the relative's disease	4	0

4. Are you obliged to perform any complementary job for extra money? Yes (0) No (5)

As frequently as before	5
Rarely	4
Somewhat less	3
Often	2
Very frequently	1

Never	0
Perform other job for reasons unconnected to the relative's disease	3

II. Social and leisure activities

5. Do you have time for different kinds of leisure activities in spite of your involvement into the patient's care? Yes (3) No (0)

As frequently as before	3
Somewhat more than before	4
Somewhat less than before	2
Rarely	1
Never	0
Never did	3

6. Does care of the patient allow you run the household? Yes (3) No (0)

	Now I have more to do	As much as previously	Somewhat less	Very rarely	Never	Never did
Buying food	2	3	2	1	0	3
Making laundry	2	3	2	1	0	3
Cleaning house	2	3	2	1	0	3
Cooking	2	3	2	1	0	3
Other (indicate)	2	3	2	1	0	3

7. Does care of patient allow you to give a hand to you parents and other relatives? Yes (3) No (0)

More frequently than before as I have now stopped work	4
As frequently than before	3
Somewhat less frequently	2
Very rarely	1
Never	0
Never did	3
More frequently than before as now it is my responsibility	2

8. Do you continue to discuss family plans and problems with your ill relative? Yes (3) No (0)

More often than before	4
------------------------	---

As often as before	3
A little less often than before	2
Very rarely	1
Never	0
Never did before	3

9. Does the care of our relative let you to continue to attend to the needs of your children or the grandchildren as well as you did before?

Yes (3) No (0)

	More frequently than before as I have now stopped work	As frequently as before	Somewhat less frequently	Very rarely	Never	Never did	More frequently than before as now it is my responsibility
To control and help children in scholarship	4	3	2	1	0	3	2
To take children to school, to sport activities or for a walk	4	3	2	1	0	3	2
To take children to theatres, museums, etc.	4	3	2	1	0	3	2
Other (indicate)	4	3	2	1	0	3	2

III. Responsibilities of the care-giver to help the patient in his everyday living

10. Does the regular everyday care and attention to the chronically disabled person make you depressed? Yes (0) No (3)

The mood is the same as before	5
Continuous depression (a week or more)	3
Stable depression with weight loss and insomnia	0

Depression for reasons unconnected with relative's disease	5
--	---

11. Can the patient stay at home by himself while the family members are out or away? Yes (3) No (0)

Without assistance he is able to: Always Sometimes Never

	Always	Sometimes	Never
Dress	2	1	0
Make the bed	2	1	0
Warm up food	2	1	0
Take food left for him wrapped up or in container)	2	1	0

12. Does your patient need assistance when using public transport or car-driving? Yes (0) No (3)

Never needs assistance	3
Somewhat more often than before	2
Very often	1
Always needs assistance	0
Needed assistance before disease started	3

13. Can your patient regularly take the prescribed medicine by himself? Yes (3) No (2)

Always	2
Sometimes	1
Never	0

14. Can your relative take a bath without assistance? Yes (3) No (0)

Always	2
Sometimes	1
Never	0

15. Can your patient move around without assistance? Yes (3) No (0)

Without assistance he is able to:

	Always	Sometimes	Never
Visit his therapist	2	1	0
Go for a walk or	2	1	0



shopping			
Move around inside the whole house	2	1	0
Go to the lavatory	2	1	0
Get seated on the bed	2	1	0

16. Can your relative call for a physician by himself? Yes (3) No (0)

Always	2
Sometimes	1
Never	0

14. Annex 3

14.1. FES-I

Beneficiary: Informal Care Giver

Provider: self-administered questionnaire

To distribute at the enrolment period and at the end of the experimentation

Expected average time for the filling in: 10-15 minutes

Now we would like to ask some questions about how concerned you are about the possibility of falling. For each of the following activities, please circle the opinion closest to your own to show how concerned you are that you might fall if you did this activity. Please reply thinking about how you usually do the activity. If you currently don't do the activity (e.g. if someone does your shopping for you), please answer to show whether you think you would be concerned about falling IF you did the activity.

	Not at all concerned	Somewhat concerned	Fairly concerned	Very concerned
1 Cleaning the house (e.g. sweep, vacuum or dust)	1	2	3	4
2 Getting dressed or undressed	1	2	3	4
3 Preparing simple meals	1	2	3	4
4 Taking a bath or shower	1	2	3	4
5 Going to the shop	1	2	3	4
6 Getting in or out of a chair	1	2	3	4
7 Going up or down stairs	1	2	3	4
8 Walking around in the neighbourhood	1	2	3	4
9 Reaching for something above your head or on the ground	1	2	3	4

D4.3 – Analysis of improved quality of life of involved users and carers – first version

File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx

Page: 41 of 45

10 Going to answer the telephone before it stops ringing	1	2	3	4
11 Walking on a slippery surface (e.g. wet or icy)	1	2	3	4
12 Visiting a friend or relative	1	2	3	4
13 Walking in a place with crowds	1	2	3	4
14 Walking on an uneven surface (e.g. rocky ground, poorly maintained pavement)	1	2	3	4
15 Walking up or down a slope	1	2	3	4
16 Going out to a social event (e.g. religious service, family gathering or club meeting)	1	2	3	4

15. Annex 4

15.1. PE General satisfaction of life

Beneficiary: Primary users

Provider: self-administered questionnaire

To distribute at the enrolment period and at the end of the experimentation

Expected average time for the filling in: 5 minutes

How do you assess the proficiency of formal caregivers, who take care of you?	<input type="checkbox"/> Much higher than expected
	<input type="checkbox"/> Exceeding expectations
	<input type="checkbox"/> As expected
	<input type="checkbox"/> Worst expectations
	<input type="checkbox"/> Much worse than expected
How do you assess the availability (helpfulness) of formal caregivers who take care of you?	<input type="checkbox"/> Much higher than expected
	<input type="checkbox"/> Exceeding expectations
	<input type="checkbox"/> As expected
	<input type="checkbox"/> Worst expectations
	<input type="checkbox"/> Much worse than expected
How do you assess the facilities of the healthcare establishments?	<input type="checkbox"/> Much higher than expected
	<input type="checkbox"/> Exceeding expectations
	<input type="checkbox"/> As expected
	<input type="checkbox"/> Worst expectations
	<input type="checkbox"/> Much worse than expected
Please indicate the general satisfaction regarding the assistance received	<input type="checkbox"/> Very Satisfied
	<input type="checkbox"/> Averagely satisfied
	<input type="checkbox"/> Satisfied
	<input type="checkbox"/> Not totally satisfied
	<input type="checkbox"/> Dissatisfied

D4.3 – Analysis of improved quality of life of involved users and carers – first version

File: D.4.3 – Analysis of improved quality of life of involved users and carers – first version.docx

Page: 42 of 45



Please indicate the general satisfaction regarding the formal/informal caregivers, who take care of you	<input type="checkbox"/> Very Satisfied
	<input type="checkbox"/> Averagely satisfied
	<input type="checkbox"/> Satisfied
	<input type="checkbox"/> Not totally satisfied
	<input type="checkbox"/> Dissatisfied
Please indicate the general satisfaction level regarding the relatives, who take care of you	<input type="checkbox"/> Very Satisfied
	<input type="checkbox"/> Averagely satisfied
	<input type="checkbox"/> Satisfied
	<input type="checkbox"/> Not totally satisfied
	<input type="checkbox"/> Dissatisfied
How much do you consider that your current health condition causes a stressful situation?	<input type="checkbox"/> Very
	<input type="checkbox"/> Quite
	<input type="checkbox"/> Not very
	<input type="checkbox"/> Nota at all
How much your health condition influences the relationships with the other people?	<input type="checkbox"/> Very
	<input type="checkbox"/> Quite
	<input type="checkbox"/> Not very
	<input type="checkbox"/> Nota at all
How much are you satisfied of your current living conditions?	<input type="checkbox"/> Very Satisfied
	<input type="checkbox"/> Averagely satisfied
	<input type="checkbox"/> Satisfied
	<input type="checkbox"/> Not totally satisfied
	<input type="checkbox"/> Dissatisfied

15.2. ICG General satisfaction of life

Beneficiary: Informal Caregiver

Provider: self-administered questionnaire

To distribute at the enrollment period and at the end of the experimentation

Expected average time for the filling in: 5 minutes

The elderly care allowed you to increase your abilities and skills	<input type="checkbox"/> Yes
	<input type="checkbox"/> No
The person you assist proves appreciation regarding what you do for him/her	<input type="checkbox"/> Yes
	<input type="checkbox"/> No
Do you have difficulty to reconcile the elderly care with your others engagements	<input type="checkbox"/> Much more than expected
	<input type="checkbox"/> More than expected
	<input type="checkbox"/> As expected
	<input type="checkbox"/> Less than expected
	<input type="checkbox"/> Much less than expected



How much your health has been affected by the effort taken in the elderly care	<input type="checkbox"/> Much more than expected <input type="checkbox"/> More than expected <input type="checkbox"/> As expected <input type="checkbox"/> Less than expected <input type="checkbox"/> Much less than expected
How much your social life has been affected by the effort taken in the elderly care	<input type="checkbox"/> Much more than expected <input type="checkbox"/> More than expected <input type="checkbox"/> As expected <input type="checkbox"/> Less than expected <input type="checkbox"/> Much less than expected
How much are you satisfied from your relationship with the person you care?	<input type="checkbox"/> Very Satisfied <input type="checkbox"/> Averagely satisfied <input type="checkbox"/> Satisfied <input type="checkbox"/> Not totally satisfied <input type="checkbox"/> Dissatisfied
From your point of view, the information quality regarding the assistance of formal caregivers is:	<input type="checkbox"/> Much higher than expected <input type="checkbox"/> Exceeding expectations <input type="checkbox"/> As expected <input type="checkbox"/> Worst expectations <input type="checkbox"/> Much worse than expected
How do you assess the proficiency of formal caregivers, who help you?	<input type="checkbox"/> Much higher than expected <input type="checkbox"/> Exceeding expectations <input type="checkbox"/> As expected <input type="checkbox"/> Worst expectations <input type="checkbox"/> Much worse than expected
How do you assess the alacrity of formal caregivers in the needs satisfaction of the person you assist?	<input type="checkbox"/> Much higher than expected <input type="checkbox"/> Exceeding expectations <input type="checkbox"/> As expected <input type="checkbox"/> Worst expectations <input type="checkbox"/> Much worse than expected
How much are you satisfied of the interaction with the formal caregivers	<input type="checkbox"/> Very Satisfied <input type="checkbox"/> Averagely satisfied <input type="checkbox"/> Satisfied <input type="checkbox"/> Not totally satisfied <input type="checkbox"/> Dissatisfied
How much are you satisfied of your current living conditions?	<input type="checkbox"/> Very Satisfied <input type="checkbox"/> Averagely satisfied <input type="checkbox"/> Satisfied <input type="checkbox"/> Not totally satisfied <input type="checkbox"/> Dissatisfied



15.3. FCG General satisfaction of life

Beneficiary: Formal Caregiver

Provider: self-administered questionnaire

To distribute at the enrollment period and at the end of the experimentation

Expected average time for the filling in: 5 minutes



The elderly care allowed you to increase your professional abilities and skills	<input type="checkbox"/> Yes
	<input type="checkbox"/> No
The people you assist proves appreciation regarding what you do for them	<input type="checkbox"/> Yes
	<input type="checkbox"/> No
How much your life's quality has been affected by the effort taken in the care of your patients	<input type="checkbox"/> Much more than expected
	<input type="checkbox"/> More than expected
	<input type="checkbox"/> As expected
	<input type="checkbox"/> Less than expected
	<input type="checkbox"/> Much less than expected
How much are you satisfied of the interaction with your patients	<input type="checkbox"/> Very Satisfied
	<input type="checkbox"/> Averagely satisfied
	<input type="checkbox"/> Satisfied
	<input type="checkbox"/> Not totally satisfied
	<input type="checkbox"/> Dissatisfied
How much are you satisfied of the interaction with the informal caregivers	<input type="checkbox"/> Very Satisfied
	<input type="checkbox"/> Averagely satisfied
	<input type="checkbox"/> Satisfied
	<input type="checkbox"/> Not totally satisfied
	<input type="checkbox"/> Dissatisfied
How much are you satisfied of the interaction with the formal caregivers	<input type="checkbox"/> Very Satisfied
	<input type="checkbox"/> Averagely satisfied
	<input type="checkbox"/> Satisfied
	<input type="checkbox"/> Not totally satisfied
	<input type="checkbox"/> Dissatisfied
How much are you satisfied of your current living conditions?	<input type="checkbox"/> Very Satisfied
	<input type="checkbox"/> Averagely satisfied
	<input type="checkbox"/> Satisfied
	<input type="checkbox"/> Not totally satisfied
	<input type="checkbox"/> Dissatisfied