

iVICQ

iMTA Valuation of Informal Care Questionnaire

Version 1.1 (May 2013)

Hoefman RJ, Van Exel NJA, Brouwer WBF
Institute of Health Policy & Management /
Institute for Medical Technology Assessment

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MANUAL

Version 1.0 (December 2011)

Hoefman RJ, Van Exel NJA, Brouwer WBF
institute of Health Policy & Management /
institute for Medical Technology Assessment

1 Aim and structure of the iVICQ

1.1 Aim of the questionnaire & manual

The aim of the iVICQ is to facilitate and promote an accurate description of providing informal care, its effects on informal caregivers, and how such effects are included in economic evaluations of health care interventions.

The manual provides background information on the iMTA Valuation of Informal Care Questionnaire (iVICQ), which was developed by Erasmus University Rotterdam's institute of Health Policy & Management (iBMG; <http://www.ibmg.nl>) and institute for Medical Technology Assessment (iMTA; <http://www.imta.nl>).

The manual provides background information and instructions for using selected survey instruments and valuation methods in the context of the questionnaire. The survey instruments were developed by or included in recent informal care studies of iBMG and iMTA. The iVICQ therefore provides a comprehensive and coherent selection of instruments for informal care research in the field of health economics based on research experience. It is not meant to be an extensive overview of all subjects or survey instruments related to measuring and valuing informal care.

1.2 Structure of the questionnaire

The iVICQ starts with the definition of informal care and corresponding selection questions for respondents (Section A). The questionnaire, its aim, and the term 'informal care' are then introduced to the respondent (Section B). The first part of the iVICQ aims to *measure* important background characteristics of informal caregivers (Section C), care recipients (Section D), and the informal care situation (Section E). The second part of the questionnaire relates to the *valuation* of informal care by monetary (Section G) and non-monetary (Section F) methods.

The outline of the questionnaire is as follows:

<i>Section A</i>	Definition and selection questions informal care
<i>Section B</i>	Introduction text questionnaire
<i>Section C</i>	Background characteristics informal caregiver
<i>Section D</i>	Background characteristics care recipient
<i>Section E</i>	Characteristics of the informal care situation
<i>Section F</i>	Subjective burden and well-being (non-monetary valuation of informal care)
<i>Section G</i>	Monetary valuation of informal care
<i>Section G.1</i>	Opportunity cost method
<i>Section G.2</i>	Proxy good method
<i>Section G.3</i>	Contingent valuation
<i>Section G.4</i>	Well-being method

Researchers can use the entire iVICQ, sections of it, or single survey instruments, keeping in mind that some questions appear in more than one section. Repeated questions are referenced in the manual.

The different valuation methods in Section F and Section G have pros and cons, and are sometimes combined with other measures, such as health related quality of life (QoL). When using different valuation methods, the researcher should be aware of the risk of double counting costs or effects in economic evaluations. An extensive discussion of this topic can be found in *Brouwer et al. 2010*, *Koopmanschap et al. 2008*, *Van den Berg et al. 2004*, and *Van Exel et al. 2008a*.

1.3 Key questionnaire

The iVICQ includes a relatively large number of questions. If researchers cannot or do not include all questions in their research, we advise using the following as a minimum set:

<i>Section C</i>	Caregivers' gender (question C1), age (question C2) and health (question C11)
<i>Section D</i>	Patients' gender (question D1), age (question D2), health (question D3), and relationship to the informal caregiver (question D6)
<i>Section E</i>	Duration of informal care (question E1) and total number of hours consumed per week (questions E3, E4 and E5)
<i>Section F</i>	Self-rated burden scale (question F1), CarerQoL instrument (questions F4 and F5), and Assessment of caregiving situation scale (question F6)
<i>Section G</i>	Contingent valuation method: willingness-to-accept (question G.3.1)

1.4 Minimum variant

Some evaluation studies, such as randomized controlled trials (RCTs), include a very small number of informal care questions, even in situations where informal care is relevant. The following set of questions can be used as a 'quick-scan'.

Measuring objective burden and costs:

- The number of hours per week (questions E3, E4 and E5). To derive a cost estimate: multiply these numbers of hours by an amount per hour (see Table 2).

Measuring effects:

- Health informal caregiver (question C11) and subjective burden (question F1).

1.5 Permission to use and reference

The iVICQ is available for use in part or in total without prior permission from the authors. Its use is the responsibility of the researcher. Please reference the use of this document in any publication:

Hoefman RJ, Van Exel NJA, Brouwer WBF. iMTA Valuation of Informal Care Questionnaire (iVICQ). Version 1.0 (December 2011). Rotterdam: iBMG / iMTA, 2011. [retrieved from www.bmg.eur.nl/english/imta/publications/manuals_questionnaires/ on dd/mm/yyyy]

Comments about or suggestions for improving the iVICQ should be directed to its first author, Renske Hoefman (hoefman@bmg.eur.nl).

2 Content of the questionnaire

2.1 Section A: Definition and selection questions informal care

What is informal care?

Informal care is here defined as:

'long-term care or support lent on voluntarily basis to a family member, friend, or acquaintance for physical or mental health problems or problems due to aging'.

Thus, not all care and support provided to family or friends is informal care, only the additional activities following a health-related need for care or support.

This definition overlaps with those often used in the literature. In the context of the Netherlands, it largely resembles that used by Statistics Netherlands (CBS) and the Netherlands Institute for Social Research (SCP) in their research on informal care.

Important aspects of the definition of informal care are:

- The basis of the care is voluntarily;
- The care is lent within a (prior) social relationship not restricted to family members;
- Informal care only includes care and support due to health problems or aging;
- Care or support is considered informal care when it has been provided for more than two weeks. Lending care to a person with a recovery period of less than two weeks is thus not considered informal care in our definition;
- Some countries provide an opportunity to reward informal caregivers financially for their activities, by for example tax policies or payments from a care recipient's personal care budget. Therefore, our definition of informal care is not restricted to 'unpaid' care.

Who is an informal caregiver?

Informal caregivers can be selected prior to or upon data collection by the researcher. Two selection questions can be used (A1 and A2). A respondent is considered an informal caregiver if she/he answers 'yes' to both questions.

2.2 Section B: Introducing the questionnaire to respondents

The term 'informal care' is explained by using the definition of Section A and citing examples of informal care tasks. Section B shows how respondents and care recipients are referred to in the questionnaire. A general reference can be replaced by a more specific one, such as 'your mother' instead of 'her' in a digital or internet survey.

2.3 Section C: Background characteristics informal caregiver

The background characteristics of informal caregivers included in the questionnaire are:

<i>Question C1</i>	Gender
<i>Question C2</i>	Age
<i>Question C3</i>	Educational level
<i>Questions C4, C5, C6</i>	Household composition
<i>Question C7</i>	Paid work
<i>Question C8</i>	Unpaid work
<i>Question C9</i>	Financial compensation for providing informal care
<i>Question C10</i>	Monthly net household income
<i>Question C11</i>	Health

Educational level

We did not include a question on highest attained educational level of the informal caregiver, as classification systems are country specific. We advise researchers to use a commonly used classification in their country, such as what is used by the national statistics office.

Financial compensation

Informal caregivers may receive financial compensation for their time and efforts. In the Netherlands, for instance, persons in need of care can apply for a personal care budget (also known as cash benefits) to manage their care situation themselves and arrange care according to their preferences. Both formal and informal caregivers can be paid from this budget. Whether a question on financial compensation of caregivers is useful depends on the arrangements of the country or region of study.

Income

The question on income is also country specific and can be adjusted if needed. We prefer a closed-ended format of monthly net household income with many categories, which can then be grouped within low, middle, and high income levels for analysis.

Health

A visual analogue scale (VAS) with start- and endpoints of 'worst possible health' and 'best possible health' (question C11) is included in the questionnaire to provide an indication of the health status of the informal caregiver. More elaborate generic measures of health are also available for informal care research, such as the SF-6D (*Brazier et al. 2002*) or the EuroQol (*EuroQol Group 1990*). The EuroQol was often used in informal care studies conducted by the iBMG/iMTA (*e.g., Bobinac et al. 2010, Van Exel et al. 2004a, Van den Berg et al. 2005b, Van Exel et al. 2005, and Brouwer et al. 2004*). More information on the EuroQol and its scientific and commercial uses can be found on the EuroQol group website (<http://www.euroqol.org>).

In the case of economic evaluation and/or RCT, we advise researchers to use the same generic health measure for the patient and the informal caregiver to increase comparability and possibility of aggregating effects in patients and informal caregivers.

2.4 Section D: Background characteristics care recipient

Background characteristics of the care recipient included in the questionnaire are:

<i>Question D1</i>	Gender
<i>Question D2</i>	Age
<i>Questions D3, D4, D5</i>	Health
<i>Question D6</i>	Relationship between informal caregiver and care recipient

Health

Health is measured by a general valuation (question D3), type of health problem (question D4) and independence in activities of daily living (question D5). Researchers may choose a more elaborate measure. More information can be found under Section C above.

The Katz Index of Independence in Activities of Daily Living (ADL) (*Katz et al. 1970, Katz et al. 1963*) (question D5) consists of six questions on the ability of the care recipient in the areas of bathing, dressing, toileting, transferring, continence, and feeding. For each question, respondents receive 1 point for the ability to perform the activity without supervision, direction, or personal assistance. Summed scores range from 0 to 6, with higher scores indicating higher levels of independence. The Katz index can be obtained from <http://www.hartfordign.org> and/or <http://ConsultGeriRN.org>.

2.5 Section E: Characteristics of the informal care situation

The questions in this section can be used to describe the informal care situation, such as the number of hours per week spent giving care and where it occurs. Such objectively measurable characteristics of informal care are also known in the literature as the 'objective burden' of informal care.

The characteristics of the informal care situation included in the questionnaire are:

<i>Question E1</i>	Duration of informal care
<i>Questions E2, E3, E4 and E5</i>	Intensity of informal care
<i>Question E6</i>	Need for permanent surveillance
<i>Questions E7 and E8</i>	Care recipient's living situation
<i>Questions E9 and E10</i>	Use of professional care
<i>Question E11</i>	Need for professional care
<i>Question E12</i>	Use of non-professional care

Intensity of informal care

Time spent on informal care can be described in terms of the spread of the care given over the week (question E2) and the number of hours of care per week. The iVICQ distinguishes three main types of caregiving tasks: household activities (question E3), personal care (question E4) and practical support (instrumental activities of daily living; IADL) (question E5).

Questions E3, E4, and E5 give some examples of each type of caregiving task derived from the most common caregiving situation, i.e., an informal caregiver lending care to a non-institutionalised care recipient.

Studies that focus on informal care to institutionalised care recipients should consider adjusting the examples:

Question E3: For example, food preparation, cleaning, washing, ironing, sewing, or shopping.

Question E5: For example, moving or travelling outside the house, including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts (e.g., doctors' appointments or therapy), organizing physical aids and taking care of financial matters (e.g., insurance).

If desired, these three questions on intensity of care can be replaced by a more detailed set of questions such as those used in *Bobinac et al. 2010, Van den Berg et al. 2005b, Van Exel et al. 2005, Brouwer et al. 2004, Bobinac et al. 2011, Van Exel et al. 2002, and Brouwer et al. 2006*. Such instruments split the three types of caregiving tasks (household activities, personal care and practical support) into 16 care and support activities. Respondents can indicate whether they perform each of the 16 activities, and if so, for how many minutes per day or hours per week. This comprehensive list provides more insight in the specific type of activities performed and provides an indication of the complexity of caregiving (in terms of the number of tasks performed), which is related to the experienced subjective burden of caregiving (*Van Exel et al. 2004a*).

We would like to know how much time you spend on giving informal care to your care recipient. Please consider the **past week!**

Did you spend time during the last week on the following activities in her/his house?

		Minutes per day	or	Hours per week
Preparation of food and drinks?	<input type="checkbox"/> yes →	<input type="text"/>	or	<input type="text"/>
	<input type="checkbox"/> no			
Cleaning the house?	<input type="checkbox"/> yes →	<input type="text"/>	or	<input type="text"/>
	<input type="checkbox"/> no			
Washing, ironing and sewing?	<input type="checkbox"/> yes →	<input type="text"/>	or	<input type="text"/>
	<input type="checkbox"/> no			
Taking care of and playing with your children?	<input type="checkbox"/> yes →	<input type="text"/>	or	<input type="text"/>
	<input type="checkbox"/> no			
Shopping?	<input type="checkbox"/> yes →	<input type="text"/>	or	<input type="text"/>
	<input type="checkbox"/> no			
Maintenance work, odd jobs, gardening?	<input type="checkbox"/> yes →	<input type="text"/>	or	<input type="text"/>
	<input type="checkbox"/> no			

Did you spend time during the last week assisting her/him with the activities below?

			Minutes per day	or	Hours per week
Personal care (dressing/undressing, washing, combing, shaving)?	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				
Going to the toilet?	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				
Moving around the house?	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				
Eating and drinking?	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				

Did you spend time during the last week assisting her/him with the activities below?

			Minutes per day	or	Hours per week
Mobility outside the house (assistance with walking or wheelchair)?	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				
Making trips and visiting family or friends?	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				
Visiting a doctor or the hospital	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				
Organizing help, physical aids or house adaptations?	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				
Taking care of financial matters like insurance?	<input type="checkbox"/> yes	→	<input type="text"/>		<input type="text"/>
	<input type="checkbox"/> no				

Living situation of care recipient

Question E7 establishes whether the informal caregiver and care recipient share a household and, if not, question E8 establishes whether the care recipient lives independently or in a care institution.

Studies on informal care for institutionalised persons may additionally ask about the total time spent visiting the care recipient: 'How many hours did you spend visiting her/him during the last week?'

2.6 Section F: Subjective burden, health and well-being (non-monetary valuation)

The impact of informal care on the informal caregiver can be expressed in different terms, such as subjective burden or the effect on the informal caregiver's health or well-being.

Subjective burden

Subjective burden refers to the impact of caregiving as perceived by informal caregivers. It is thus concerned with the caregiver's *experience* with their caregiving activities, which is not necessarily related strongly to their objective burden (*Koopmanschap et al. 2008, Van Exel et al. 2008a, Van Exel et al. 2004a*).

Subjective burden is a frequently used measure in informal care studies because it provides important information about how informal caregivers are coping with their caregiving situation. Subjective burden may also be relevant in clinical settings and research on respite care for informal caregivers. An important note here is that subjective burden is not an economic evaluation method.

Several generic and disease-specific instruments are available to measure subjective burden. Most contain different aspects such as experienced mental health, physical health, and social and financial problems (*Brouwer et al. 2010, Deeken et al. 2003, Van Exel et al. 2004b*). The instruments provide a detailed description of subjective burden, and almost all focus exclusively on the problems that informal caregivers may experience.

Four instruments are used in this questionnaire to measure subjective burden:

<i>Question F1</i>	Caregiver Strain Index
<i>Question F2</i>	Self-rated burden scale
<i>Question F3</i>	Perseverance time
<i>Question F6</i>	Assessment of informal care situation scale

The iVICQ includes the Caregiver Strain Index plus (CSI+), which is an extended version of the often-used Caregiver Strain Index (*Robinson 1983, Al-Janabi et al. 2010*). The original CSI measures subjective burden based on 13 negative dimensions. The CSI+ (question F1) adds five positive dimensions (questions F1.3, F1.6, F1.11, F1.14 and F1.18), which are spread over the instrument to create balance in positive and negative aspects of informal care (*Al-Janabi et al. 2010*).

Respondents can indicate whether an item corresponds to their situation by choosing 'yes' or 'no'. Based on this, a non-weighted sum score can be calculated. A 'yes' has a score of '1' with negative dimensions and a score of '-1' with positive dimensions. A 'no' has a score of '0' with both items. The summed scores range from -5 to 13 (CSI+) and 0 to 13 (CSI) (*Al-Janabi et al. 2010*). A higher score means a higher subjective burden. Informal caregivers are considered to be experiencing substantial strain if their score is 7 or higher on the original CSI (*Robinson 1983*).

Like most subjective burden instruments, the CSI+ uses a non-weighted sum score to indicate the level of subjective burden. While such a sum score in combination with a cut-off point can be useful to diagnose substantial burden, it is not clear whether it gives a plausible estimate of the burden as perceived by the caregiver. For instance, not all problems are experienced as problematic or equally problematic by caregivers (*Van Exel et al. 2004a*). A second instrument in the iVICQ, the self-rated burden scale (SRB) (*Van Exel et al. 2004b*), takes this into account by providing an overall description of subjective burden, supposedly including all positive and negative effects of caregiving.

The self-rated burden scale (SRB) (question F2) measures subjective burden of informal care with a horizontal visual-analogue scale (VAS), judging the burden of caregiving on a scale ranging from (0) 'not straining at all' to (10) 'much too straining'. The SRB is a generic measure and can therefore be used in different informal care populations and research settings (*Van Exel et al. 2008a*). The SRB may also be used as a screening tool for severe burden among informal caregivers (*Brouwer et al. 2006, Van Exel et al. 2004b, Hoefman et al. 2011a, Hoefman et al. 2011b*).

Perseverance time (question F3) queries the length of time caregivers expect to be able to continue performing their current informal care tasks, ranging from less than two weeks to more than two years (*Kraijo et al. 2011*). Like measures of subjective burden, perseverance time is a diagnostic measure. The time caregivers anticipate being able to cope with caregiving has as far as we know no prognostic value.

The Assessment of the informal care situation (ASIS) (question F6) asks informal caregivers to judge the desirability of their caregiving situation, using a horizontal visual-analogue scale (VAS) ranging from (0) the 'worst imaginable caregiving situation' to (10) the 'best imaginable caregiving situation'. The ASIS provides a valuation of the caregiving situation (*Hoefman et al. 2011a*).

Health

The effect of providing informal care on the health of caregivers is an important topic (*Van Exel et al. 2008a, Bobinac et al. 2010, Brouwer et al. 2004, Bobinac et al. 2011, Payakachat et al. 2011*).

An often-used measure of health in informal care studies is the EuroQol-5D (*EuroQol Group 1990*), e.g., *Van Exel et al. 2004a, Hoefman et al. 2011a, Poley et al. 2011*.

Obviously, only the influence of providing informal care or the influence of an intervention related to the informal caregiver's quality of life is of importance here. This can be assessed by (i) relating health to informal care (*Bobinac et al. 2011*), (ii) measuring changes in health in the context of an intervention, or (iii) comparing quality of life of caregivers to the quality of life of the population at large (*Brouwer et al., 2004; Poleij et al., 2011*).

Changes in health can be measured with validated instruments such as the EQ-5D (section 2.3). This information can be expressed in Quality-Adjusted Life Years (QALYs) (e.g. *Drummond et al. 2005*) for use with national tariffs, for example (*Dolan 1997, Lamers et al. 2006*), as is usually done in economic evaluations. Caregiver QALYs can be used in cost-utility studies, keeping in mind that the valuation of health effects of informal care in terms of QALYs comprises a partial valuation of caregiving only (e.g., *Brouwer et al. 2010, Koopmanschap et al. 2008*).

Well-being

Two well-being instruments are included in the questionnaire:

Questions F4 and F5	Care-related Quality of Life instrument N.B.: Question F5 is duplicate if Section G.4 is also used
Questions F5 and F7	Process Utility

CarerQol

The Care-related Quality of Life instrument (CarerQol) combines a subjective burden measure with a valuation of informal care in terms of well-being. The instrument was designed to provide a comprehensive description of the caregiving situation (CarerQol-7D: question F4), and to value informal care in an economic sense (CarerQol-VAS: question F5) (*Brouwer et al. 2006*). The development of the CarerQol was based on the EuroQol instrument (*EuroQol Group 1990*).

The CarerQol-7D comprises five negative and two positive dimensions of lending informal care derived from a literature review of subjective burden measures. The five negative dimensions are (i) relational problems, (ii) mental health problems, (iii) problems combining daily activities with care, (iv) financial problems, and (v) physical health problems. The two positive dimensions are (i) fulfilment from caregiving and (ii) support with lending care. Respondents are asked to indicate whether an item applies to them with three possible responses: (i) no, (ii) some, and (iii) a lot. The combination of items and answering categories yields 2187 (= 3⁷) caregiving situations.

Answers on the negative dimensions of the CarerQol-7D receive value of 0 (a lot), 1 (some) and 2 (no); answers on the positive dimensions receive a value of 0 (no), 1 (some), and 2 (a lot). Summing the values for the seven dimensions, a score of 0 thus translates to the worst informal care situation (a lot of problems and no support or fulfilment); the higher the score, the better the situation. Applications of this instrument can be found in *Brouwer et al. 2006, Hoefman et al. 2011a, Hoefman et al. 2011b, Payakachat et al. 2011, and Van Exel et al. 2008b*.

Recently, a tariff has become available for the CarerQol (*Hoefman et al. 2013*), which enables researchers to calculate a weighted sum score of the CarerQol-7D, taking the severity of problems into account (Table 1). The tariff is based on Dutch preferences for different caregiving situations and therefore concern Dutch national tariffs. Using the weighted sum score, the worst caregiving situation receives a score of 0, while the best now has a score of 100. The scores between 0 and 100 can be calculated using the tariffs in Table 1.

Table 1. National tariff CarerQol-7D

Dimension	Tariff for score		
	no	some	a lot
Fulfilment	0.0	13.6	19.7
Relational problems	14.7	10.6	0.0
Mental health problems	13.3	9.3	0.0
Problems combining daily activities	10.0	6.4	0.0
Financial problems	14.3	10.6	0.0
Support	0.0	4.7	6.5
Physical health problems	15.1	15.1	0.0
plus: a 'bonus' for:	no	yes	
No mental health problems and no physical health problems	0.0	6.6	

Syntax files for calculating the tariffs for the CarerQol-7D in SPSS or Stata can be found in Annex. A numerical example is presented below.

NUMERICAL EXAMPLE CARERQOL-7D

Suppose that the answers of a respondent on the CarerQol-7D are:

- *some* fulfilment
- *a lot of* relational problems
- *no* mental health problems
- *some* problems combining daily activities
- *no* financial problems
- *a lot of* support
- *no* physical health problems

The CarerQol-7D score is: $13.6 + 0 + 13.3 + 6.4 + 14.3 + 6.5 + 15.1 + 6.6 = 75.8$

It is important to keep in mind when calculating the CarerQol-7D score that respondents get a 'bonus' of 6.6 for having neither mental nor physical health problems.

The CarerQol-VAS, a valuation component, is a horizontal visual-analogue scale (VAS) measuring well-being of the informal caregiver in terms of general happiness, ranging from completely unhappy (=0) to completely happy (=10) (Brouwer *et al.* 2006). The main advantage of using a valuation of informal care in terms of a broad outcome measure of happiness is that different effects that occur due to providing informal care, such as health or financial problems, are taken into account in the valuation. We must consider, however, that such a broad outcome measure may also be influenced by effects outside the direct scope of caregiving, such as income level and social contacts.

The CarerQol can also be combined with less broad outcome measures such as the SRB (question F1) and the ASIS (question F6), which value informal care in terms more specifically related to caregiving: subjective burden and desirability of the caregiving situation.

The results of the CarerQol can be applied in informal care research focusing on the burden and support of caregivers as an indication of subjective burden. In addition, the CarerQol is well-suited to economic evaluations. The data gathered with the instrument can be included in the 'effect-side' of multi-criteria or costs-consequence analyses. A cost-utility analysis is suitable when comparing interventions specifically aimed at informal caregivers in an economic evaluation. For an extensive discussion see Van Exel *et al.* 2008a.

Process utility

Process utility (PU) refers to the value attached by the informal caregiver to the process of lending informal care (Brouwer *et al.* 2005) and is calculated by taking the difference in happiness between two situations: the current situation (question F5) and a hypothetical situation in which the care tasks would be taken over by a person selected by the care recipient and caregiver, without changing the living situation of the care recipient and free of charge (question F7). This question also provides insight in the desirability of taking over care tasks by other persons.

The retrospective method asks respondents the time forgone to provide informal care:

- Time forgone of paid work due to informal care (question G.1.1)
- Time forgone of unpaid work due to informal care (question G.1.2)
- Time forgone of leisure time due to informal care (question G.1.3)

In situations where caregivers have been providing informal care for a long period, it is often difficult to answer the retrospective questions. Instead, hypothetical questions can be used in which respondents indicate which activities they would perform if informal care were not needed:

- More time spent on paid work (question G.1.4)
- More time spent on unpaid work (question G.1.4)
- More time spent on leisure (question G.1.4)

Additional questions needed for opportunity costs method:

- Gross personal income informal caregiver (question G.1.5)

In the case of no paid work or unknown income, the information needed is:

- Gender of informal caregiver (question C1)
- Age of informal caregiver (question C2)
- Educational level of informal caregiver (question C3)

More information on the opportunity cost method can be found in *Brouwer et al. 2010*, *Koopmanschap et al. 2008*, *Van den Berg et al. 2004*, and *Van den Berg et al. 2006*.

NUMERICAL EXAMPLE OPPORTUNITY COST METHOD

Suppose a respondent provides 12 hours of informal care per week, giving up the following to provide informal care:

- 1 hour paid work
- 3 hours unpaid work
- 8 hours leisure time

If the respondent's gross hourly wage rate is €30, the value of unpaid work and leisure time unknown, and the value of household activities €12.50 per hour, then the monetary value of the time forgone to provide informal care of this person is $(1 * 30) + (3 * 12.50) + (8 * 12.50) = €167.50$.

2.7.2 Section G.2: Proxy good method

The proxy good method also calculates the value of informal care by multiplying the number of hours spent on informal care by a value per hour that is derived by calculating a shadow price of a market substitute. The shadow price of informal care is the hourly wage rate of a professional caregiver.

The shadow price can vary, because tasks are provided by different wage earners, such as household help or specialized nurses. The method requires knowing the type of care tasks performed and the number of hours per week spent on them.

Questions for proxy good method:

- Time spent on informal care tasks (questions G.2.1 and G.2.3)
N.B.: Questions G.2.1 and G.2.3 are duplicates if Section E is included
- Tariff market substitute for household activities
- Tariff market substitute for personal care
- Tariff market substitute for practical support

The proxy good method is extensively discussed in *Brouwer et al. 2010*, *Koopmanschap et al. 2008*, *Van den Berg et al. 2004*, and *Van den Berg et al. 2006* and applied in *Van den Berg et al. 2006*.

NUMERICAL EXAMPLE PROXY GOOD METHOD

Suppose a respondent provides 12 hours informal care per week, comprising:

- 7 hours household activities
- 2 hours personal care
- 3 hours practical support

If the shadow price of household activities is €8.50 euro, personal care €35, and practical support €35, then the monetary value of the time forgone to provide informal care is $(7 * 8.50) + (2 * 35) + (3 * 35) = €234.50$.

2.7.3 Section G.3: Contingent valuation method

The contingent valuation method derives a monetary value of informal care by asking respondents what their minimum compensation would be to provide an extra hour of informal care (willingness-to-accept, WTA, question G.3.1), or the maximum amount they would be willing to pay to perform one hour less of informal care (willingness-to-pay, WTP, question G.3.2). Respondents are asked how much money they would need to compensate for their loss (or gain) in well-being due to a change in the level of informal care provided; only the number of hours per week changes, all other things, such as the recipient's need for care, remain the same.

In the context of informal care, WTA seems more appropriate than WTP, as WTP is often used to value gains and WTA to value losses (*Van Exel et al. 2006*); providing informal care can be seen as a loss due to the opportunity costs of time spent on caregiving. More information on WTA and WTP in the context of informal care can be found in *Van den Berg et al. 2005b*, *Van Exel et al. 2006*, *Van den Berg et al. 2005a*, and *De Meijer et al. 2010*.

Surveys conducted with a computer or internet can use various WTA and WTP question formats. An example of a WTA question with a payment scale (ranging from €0-€50 or above) is presented below. Respondents can indicate the minimum (maximum) compensation they definitely are (not) willing to receive (forgo) to provide an extra hour of informal care. After that, an ‘open-ended’ question is posed to elicit the exact amount of financial compensation. The answer usually is considered the final valuation. Additionally, respondents not willing to change the number of hours per week of informal care or not willing to receive financial compensation are asked to state their reasons.

WTA.1

Imagine that she/he needs **one extra hour of informal care** per week and that government will pay you for lending this extra hour of informal care. Please look at the numbers below, from left to right, and tick the *highest* amount that you **would definitely not** be willing to forgo to provide an extra hour of informal care.

For example: if you are certain that you would not provide the extra hour of informal care for €20 from the government, but not certain that you would forgo €22,50, tick €20.

0	5	7,50	10	12,50	15	17,50	20	22,50	25	30	35	40	45	50	higher
<input type="checkbox"/>															

- If you ticked a number between €0 and €50, go to question WTA.3.
- If you ticked ‘higher’, go to question WTA.2.

WTA.2

You stated that you want to receive more than €50 from the government to provide the extra hour of informal care. What is the maximum amount for which you **would definitely not** be willing to provide an extra hour of informal care?

- I would definitely not be willing to provide this extra hour of informal care for €
→ **Go to question WTA.5**
- I do not want to provide an extra hour of informal care, regardless of the government’s amount of compensation.
→ **Go to question WTA.6**

WTA.3

Please look at the numbers below, from right to left, and tick the lowest amount for which you **would definitely** be willing to accept to provide an extra hour of informal care.

For example: if you are certain that you would provide this extra hour of informal care for €22,50 from the government, but not certain that you would provide it for €20, tick €22,50.

0	5	7,50	10	12,50	15	17,50	20	22,50	25	30	35	40	45	50	higher
<input type="checkbox"/>															

- If you ticked a number between €0 and €50, go to WTA.5.
- If you ticked '0', go to question WTA.7.
- If you ticked 'higher', go to question WTA.4.

WTA.4

You stated that you would want more than €50 from the government to provide the extra hour of informal care. What is the *lowest* amount that you would **definitely be willing to accept** to provide an extra hour of informal care?

- I would definitely be willing to provide the extra hour of informal care for €_____.
- **Go to question WTA.5**
- I do not want to provide an extra hour of informal care regardless of how much the government might pay me.
- **Go to question WTA.6**

WTA.5

What is the **lowest** amount you would be willing to accept to provide the extra hour of informal care?

(Please take your answers to questions WTA.1 and WTA.3 into account. The amount should be higher than the answer to WTA.1 and lower than the answer to WTA.3.): €_____

- **End of WTA-questionnaire**

WTA.6

You stated that you did not want to provide an extra hour of informal care, regardless of the compensation. Could you please explain why?

- Care is the government's responsibility
- Care should be provided by professionals
- I do not have the time to provide extra informal care
- I do not have the energy to provide extra informal care
- Other: _____

→ **End of WTA-questionnaire**

WTA.7

You stated that you do not want to receive money from the government for providing an extra hour of informal care. Could you please explain why?

- A financial compensation for informal care is not appropriate
- I do not want to receive a financial compensation for informal care
- Other: _____

→ **End of WTA-questionnaire**

2.7.4 Section G.4: Well-being method

The well-being method derives the monetary value of informal care by eliciting the amount a caregiver requires as compensation for the loss in well-being due to lending informal care (*Van den Berg et al. 2004*). *Van den Berg and Ferrer-I-Carbonell 2007* have applied the well-being method in informal care research.

The following information is needed to calculate the monetary value with the well-being method:

- Happiness of the informal caregiver (question G.4.1)
NB: Question G.4.1 is duplicate if Section F is included.
- Income informal caregiver (question G.4.2)
NB: Question G.4.2 is duplicate if Section C or Section G.1 is included.
- Hours of informal care per week (question G.4.3, G.4.4 and G.4.5)
NB: Questions G.4.3, G.4.4 and G.4.5 are duplicates if Section E or Section G.2 is included.

Table 2 displays some monetary values for informal care elicited from previous studies. The values can be considered if none is available. The average is about €12.50 per hour, which is in line with the cost manual for economic evaluations in health care (*Hakkaart-van Roijen et al. 2010*).

Table 2. Monetary values of informal care in euros per hour according to method of valuation

Method	Values per hour informal care (in Euros of year)			
	Lowest		Highest	
Opportunity cost method	€10	(2001)	€17	(2001)
Proxy good method	€12	(2001)	€14	(2001)
Contingent valuation - WTA	€8	(2001)	€18	(2010)
- WTP	€7	(2001/2002)	€9	(2001/2002)
Well-being method	€9	(2001/2002)	€10	(2001/2002)

iMTA Valuation of Informal Care Questionnaire

QUESTIONNAIRE

Version 1.0 (December 2011)

Hoefman RJ, Van Exel NJA, Brouwer WBF
institute of Health Policy & Management /
institute for Medical Technology Assessment

3 iMTA Valuation of Informal Care Questionnaire (iVICQ)

Section A

A1

Do you provide care or support on a voluntarily basis to a family member, friend or other acquaintance who needs help due to physical or mental health problems or problems due to aging?

- No
- Yes

A2

Have you been providing this care or support for more than two weeks?

- No
- Yes

Section B**General introduction**

This questionnaire is concerned with the care or support that a person lends on a voluntarily basis to a family member, friend or other acquaintance needing help due to physical or mental health problems or problems due to aging. Such care or support is called informal care.

Informal care can consist of different activities, such as emotional support and surveillance, help with travelling, household activities, personal care, nursing care, or administrative activities.

In the questionnaire, the person you lend informal care to is referred to as 'she/he' or 'her/him'.

Section C

This questionnaire starts with some questions relating to you.

C1

Are you female or male?

Female

Male

C2

What is your age? _____ years

C3

What is your highest attained educational level?

...

...

C4

Do you have a partner?

No

Yes

C5

Do you have children?

No

Yes: _____ [number] children under 18 years

_____ [number] children older than 18 years

C6

Do your children live in your home?

No

Yes: _____ [number] children live in my home

C7

Do you have paid work?

- No
- Yes, I work fulltime [a contract of 36 hours or more per week]
- Yes, I work part-time: _____ hours per week.

C8

Do you have unpaid work?

Please do not consider informal care here

- No
- Yes: _____ hours per month

C9

Does the care recipient financially compensate you for the care lent to her/him?

- No
- Yes: € _____ net per month

C10

What is the income level of you and (if applicable) your partner combined?

Please state the **net household income per month**.

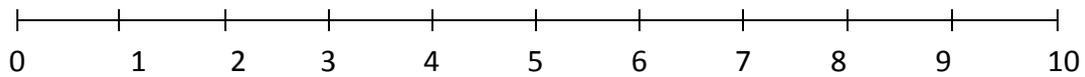
- Less than €1.000 per month
- Between €1.000 and €1.499 per month
- Between €1.500 and €1.999 per month
- Between €2.000 and €2.499 per month
- Between €2.500 and €2.999 per month
- Between €3.000 and €3.499 per month
- Between €3.500 and €3.999 per month
- Between €4000 and €4.499 per month
- Between €4.500 and €4.999 per month
- Between €5.000 and €5.999 per month
- Between €6.000 and €6.999 per month
- Between €7.000 and €7.999 per month
- More than €8.000 per month
- I do not know or I do not want to state this

How would you rate your health at the moment?

Please place a mark on the scale below that indicates how healthy you feel at the moment. A '0' means the worst health you could imagine and a '10' means the best health you could imagine.

**worst
possible
health**

**best
possible
health**



Section D

The next questions concern the person you provide informal care to.

D1

What is her/his gender?

- Female
- Male

D2

What is her/his age?

_____ years

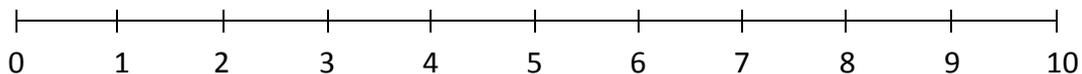
D3

How would you rate her/his health at the moment?

Please place a mark on the scale below that indicates the health of her/him at the moment. The "0" means the worst health you could imagine. The "10" means the best health you could imagine.

**worst
possible
health**

**best
possible
health**



D4

Which description, do you think, best fits her/his health problem?

Please choose one description.

- Temporary disease, disability of severe complaints with the prospect of complete recovery
- Chronic disease or disability
- Dementia or memory problems
- Mental problems
- Problems due to aging
- Terminal disease

D5

Katz Index of Independence in Activities of Daily Living (ADL)

D6

What is your relationship with her/him?

- She/he is my partner
- She/he is my mother or father
- She/he is my mother-in-law or father-in-law
- She/he is my daughter or son
- She/he is another family member
- She/he is a friend
- She/he is an acquaintance or neighbour
- Other (please specify): _____

Section E

With the following questions we would like to get an impression of the informal care you provide.

E1

How long have you been providing informal care to her/him?

- Less than a month: _____ weeks
- Less than a year: _____ months
- More than a year: _____ years

E2

On how many days per week do you usually provide care to her/him?

- 1 day
- 2 days
- 3 days
- 4 days
- 5 days
- 6 days
- 7 days

E3

How much time during the last week did you spend on **household activities** that would not have had to be performed if she/he were in good health, or if she/he could have done them?

For example, food preparation, cleaning, washing, ironing, sewing, taking care of and playing with your children, shopping or maintenance work, odd jobs, gardening.

_____ hours during the last week

E4

How much time during the last week did you spend on **personal care** for her/him?

For example, dressing/undressing, washing, hair care, shaving, going to the toilet, mobility around the house, eating and drinking, medication.

_____ hours during the last week

E5

How much time during the last week did you spend on **practical support** that would not have had to be performed if she/he were in good health, or if she/he could have done it?

For example, mobility outside the house including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts (e.g., doctors' appointments), organizing help, physical aids or house adaptations and taking care of financial matters (e.g., insurance).

_____ hours during the last week

E6

Can she/he be left alone?

- No, she/he needs continuous surveillance
- Yes, but not for more than one hour
- Yes, she/he can easily be left alone for several hours (or more)

E7

Do you share a household with her/him?

- No, I live _____ minutes of travel distance from her/him
- Yes

E8

Does she/he live independently?

- No, she/he lives in a residential or nursing home → continue to question E11
- No, she/he lives in another health institution → continue to question E11
- Yes, and she/he lives alone
- Yes, and she/he shares a household with at least one other person
- Other: _____

E9

Besides your care or support, does she/he also receive care from a professional caregiver at home?

- No
- No, but she/he is on a waiting list for professional care at home for _____ hours per week
- Yes, for _____ hours during the last week

E10

Does she/he visit a day care facility or a residential or nursing home?

- No
- No, but she/he is on a waiting list for day care for _____ hours per week
- Yes, for _____ hours during the last week

E11

Does she/he need more professional care than she/he receives at the moment?

- No
- Yes, and this care has been applied for
- Yes, and this care has not been applied for

E12

Besides your care or support, does she/he also receive care from other informal caregivers?

- No, I am the only informal caregiver
- Yes, from _____ [number] other informal caregivers,
in total for _____ hours during the last week

Section F

Providing informal care can be burdensome. The next questions deal with the burden you experience from lending care to her/him.

F1

Below we present a list of statements from other people providing informal care. We are interested in how you feel about these statements. Please take the **last week** as reference. There are no right or wrong answers; we are interested in your view.

- | | | |
|--|--|-------|
| Sleep is disturbed | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.1 |
| It is inconvenient | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.2 |
| She/he appreciates everything I do for her/him | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.3 |
| It is a physical strain | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.4 |
| It is confining | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.5 |
| Besides the care I provide to her/him, I have enough time for myself | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.6 |
| There have been family adjustments | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.7 |
| There have been changes in personal plans | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.8 |
| There have been other demands on my time | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.9 |
| There have been emotional adjustments | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.10 |
| I can handle the care for her/him fine | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.11 |
| Some behaviour is upsetting | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.12 |
| It is upsetting to find that she/he has changed so much from her/his former self | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.13 |
| I am happy to care for her/him | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.14 |
| There have been work adjustments | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.15 |
| Feeling completely overwhelmed | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.16 |
| It is a financial strain | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.17 |
| Taking care for her/him is important to me | <input type="checkbox"/> No <input type="checkbox"/> Yes | F1.18 |

F2

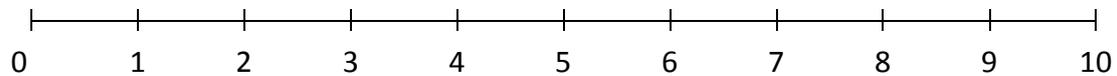
How burdensome do you feel caring for or accompanying her/him is at the moment?

Please place a mark on the scale below that indicates how burdensome you feel caring for or accompanying her/him is at the moment.

The '0' means that you feel that caring for or accompanying her/him at the moment is not straining at all; '100' means that you feel that caring for or accompanying her/him at the moment is much too straining.

***not at all
straining***

***much too
straining***



F3

If the care situation remains as it is now, how long will you be able to carry on giving care?

- Less than one week
- More than one week but less than one month
- More than one month but less than six months
- More than six months but less than one year
- More than one year but less than two years
- More than two years

We would like to form an impression of your caregiving situation.

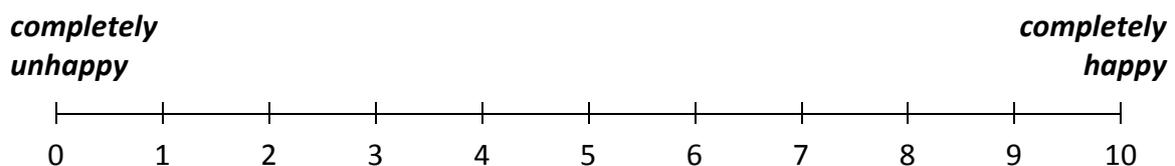
Please tick a box to indicate which description best fits your caregiving situation at the moment.

Please tick only one box per description: 'no', 'some' or 'a lot of'.

- | | | | | |
|--------|--------------------------|--------------------------|--------------------------|--|
| | no | some | a lot of | |
| I have | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | fulfilment from carrying out my care tasks. |
| I have | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | relational problems with the care receiver (<i>e.g., he/she is very demanding or behaves differently; we have communication problems</i>). |
| I have | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | problems with my own mental health (<i>e.g., stress, fear, gloominess, depression, concern about the future</i>). |
| I have | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | problems combining my care tasks with my own daily activities (<i>e.g. household activities, work, study, family, leisure activities</i>). |
| I have | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | financial problems because of my care tasks. |
| I have | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | support with carrying out my care tasks, when I need it (<i>e.g., from family, friends, neighbours, acquaintances</i>). |
| I have | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | problems with my own physical health (<i>e.g., more often sick, tiredness, physical stress</i>). |

How happy do you feel at the moment?

Please place a mark on the scale below that indicates how happy you feel at the moment.



F6

How would you rate your current caregiving situation?

Please place a mark on the scale below that best describes your caregiving situation.

The "0" means that the situation of caring for your loved one, with or without the help of others, is the worst imaginable (*for example, if you experience many problems and find no fulfillment or support in caring*). The "10" means that this is the best situation imaginable (*for example, no problems and a lot of support and fulfillment*).

**worst imaginable
caregiving
situation**

**best imaginable
caregiving
situation**



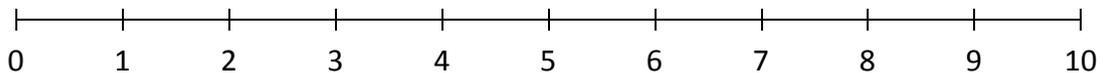
F7

Suppose a person of your and her/his choice would take over all your caregiving tasks free of charge. This person would provide all necessary care at her/his own house.

Please place a mark on the scale below to indicate how happy you would feel if all your caregiving tasks were taken over by this person.

**completely
unhappy**

**completely
happy**



Section G

Section G.1

Providing informal care can consume a lot of time. The next three questions are concerned with the activities you forgo to lend informal care.

G.1.1

Did you completely or partly give up **paid work** in order to provide informal care to her/him?

- No, I did not have paid work before
- No, I still perform the same amount of paid work
- Yes, for _____ (number) fewer hours per week since _____ (year)

G.1.2

Did you completely or partly give up **unpaid work** in order to provide informal care to her/him?

- No, I did not have unpaid work before
- No, I still perform the same amount of unpaid work
- Yes, for _____ (number) fewer hours per week since _____ (year)

G.1.3

Did you give up **time spend on leisure** in order to provide informal care to her/him?

- No, I did not have time for leisure before
- No, I still spend the same amount of time on leisure
- Yes, for _____ (number) fewer hours per week since _____ (year)

G.1.4

Suppose you did not have to provide informal care anymore. How would you spend this time: on paid work, unpaid work, or leisure?

- More paid work: No
 Yes: _____ hours per week
- More unpaid work: No
 Yes: _____ hours per week
- More leisure: No
 Yes: _____ hours per week

What is your income level?

Please state your **gross personal income per month**.

- Less than €999 per month
- Between €1.000 and €1.499 per month
- Between €1.500 and €1.999 per month
- Between €2.000 and €2.499 per month
- Between €2.500 and €2.999 per month
- Between €3.000 and €3.499 per month
- Between €3.500 and €3.999 per month
- Between €4.000 and €4.999 per month
- Between €5.000 and €5.999 per month
- Between €6.000 and €6.999 per month
- Between €7.000 and €7.999 per month
- Between €8.000 and €8.999 per month
- Between €9.000 and €9.999 per month
- More than €10.000 per month
- I do not know or I do not want to state this

Section G.2

G.2.1

How much time during the last week did you spend on household activities that would not have had to be performed if she/he were in good health, or if she/he could have done them?

For example, food preparation, cleaning, washing, ironing, sewing, taking care of and playing with your children, shopping or maintenance work, odd jobs, gardening.

_____ hours during the last week

G.2.2

How much time during the last week did you spend on personal care for her/him?

For example, dressing/undressing, washing, combing, shaving, going to the toilet, mobility around the house, eating and drinking and medication.

_____ hours during the last week

G.2.3

How much time during the last week did you spend on practical support that would not have had to be performed if she/he were in good health, or if she/he could have done it?

For example, mobility outside the house including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts (e.g., doctors' appointments), organizing help, physical aids or house adaptations and taking care of financial matters(e.g., insurance).

_____ hours during the last week

G.2.4

Do you share a household with her/him?

No, I live _____ minutes travel distance from her/him

Yes

G.3.1

Imagine that she/he needs **one extra hour of informal care** per week and that government pays you for lending this extra hour of informal care.

Which net amount would you minimally want to receive to provide one extra hour of informal care?

- €0
- €1-5
- €6-10
- €11-15
- €16-20
- €21-25
- €26-30
- €31-35
- €36-40
- €41-45
- €46-50
- Higher than €50 (please specify): € _____

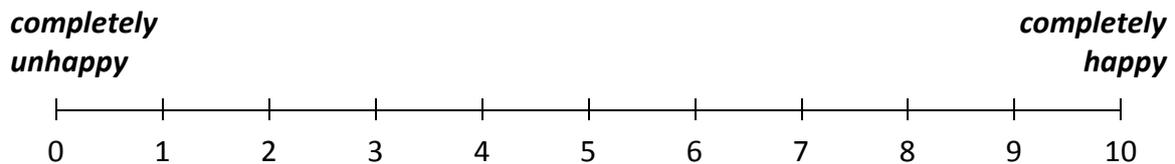
Imagine you would get the opportunity to lend **one hour informal care less** per week. Somebody will take over this care, so the total amount of care for her/him will not change.

Which amount would you maximally be willing to pay to provide one hour informal care less per week?

- €0
- €1-5
- €6-10
- €11-15
- €16-20
- €21-25
- €26-30
- €31-35
- €36-40
- €41-45
- €46-50
- Higher than €50 (please specify): €_____

How happy do you feel at the moment?

Please place a mark on the scale below that indicates how happy you feel at the moment.



What is the income level of both you and your partner?

Please state the net household income per month.

- Less than €1.000 per month
- Between €1.000 and €1.499 per month
- Between €1.500 and €1.999 per month
- Between €2.000 and €2.499 per month
- Between €2.500 and €2.999 per month
- Between €3.000 and €3.499 per month
- Between €3.500 and €3.999 per month
- Between €4000 and €4.499 per month
- Between €4.500 and €4.999 per month
- Between €5.000 and €5.999 per month
- Between €6.000 and €6.999 per month
- Between €7.000 and €7.999 per month
- More than €8.000 per month
- I do not know or I do not want to state this

G.4.3

How much time during the last week did you spend on household activities that would not have had to be performed if she/he were in good health, or if she/he could have done them?

For example, food preparation, cleaning, washing, ironing, sewing, taking care of and playing with your children, shopping or maintenance work, odd jobs, gardening.

_____ hours during the last week

G.4.4

How much time did you spend on personal care for her/him during the last week?

For example, dressing/undressing, washing, combing, shaving, going to the toilet, moving around in the house, eating and drinking and medication.

_____ hours during the last week

G.4.5

How much time during the last week did you spend on practical support that would not have had to be performed if she/he were in good health, or if she/he could have done it?

For example, mobility outside the house including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts (e.g., doctors' appointments), organizing help, physical aids or house adaptations and taking care of financial matters(e.g., insurance).

_____ hours during the last week

Annex 1: Syntax CarerQol tariff

Syntax for Stata

*d1=fulfilment
*d2=relational problems
*d3=mental health
*d4=daily activities
*d5=financial problems
*d6=support
*d7=physical health
*labels d1 en d6: 0=no, 1=some, 2=a lot
*labels d2, d3, d4, d5 and d7: 0=a lot, 1=some, 2=no

```
gen u1=.  
replace u1=0 if d1==0  
replace u1=13.6 if d1==1  
replace u1=19.7 if d1==2
```

```
gen u2=.  
replace u2=14.7 if d2==2  
replace u2=10.6 if d2==1  
replace u2=0 if d2==0
```

```
gen u3=.  
replace u3=13.3 if d3==2  
replace u3=9.3 if d3==1  
replace u3=0 if d3==0
```

```
gen u4=.  
replace u4=10.0 if d4==2  
replace u4=6.4 if d4==1  
replace u4=0 if d4==0
```

```
gen u5=.  
replace u5=14.3 if d5==2  
replace u5=10.6 if d5==1  
replace u5=0 if d5==0
```

```
gen u6=.  
replace u6=0 if d6==0  
replace u6=4.7 if d6==1
```

replace u6=6.5 if d6==2

gen u7=.

replace u7=15.1 if d7==2

replace u7=15.1 if d7==1

replace u7=0 if d7==0

gen i1=0

replace i1=6.6 if d3==2 & d7==2

gen CarerQoLTariff=u1+u2+u3+u4+u5+u6+u7+i1

Syntax for SPSS

*d1=fulfilment
*d2=relational problems
*d3=mental health
*d4=daily activities
*d5=financial problems
*d6=support
*d7=physical health
*labels d1 en d6: 0=no, 1=some, 2=a lot
*labels d2, d3, d4, d5 and d7: 0=a lot, 1=some, 2=no

```
COMPUTE u1=999.  
IF (d1=0) u1 = 0.  
IF (d1=1) u1 = 13.6.  
IF (d1=2) u1 = 19.7.
```

```
COMPUTE u2=999.  
IF (d2=2) u2 = 14.7.  
IF (d2=1) u2 = 10.6.  
IF (d2=0) u2 = 0.
```

```
COMPUTE u3=999.  
IF (d3=2) u3 = 13.3.  
IF (d3=1) u3 = 9.3.  
IF (d3=0) u3 = 0.
```

```
COMPUTE u4=999.  
IF (d4=2) u4 = 10.0.  
IF (d4=1) u4 = 6.4.  
IF (d4=0) u4 = 0.
```

```
COMPUTE u5=999.  
IF (d5=2) u5 = 14.3.  
IF (d5=1) u5 = 10.6.  
IF (d5=0) u5 = 0.
```

```
COMPUTE u6=999.  
IF (d6=0) u6 = 0.  
IF (d6=1) u6 = 4.7.  
IF (d6=2) u6 = 6.5.
```

```
COMPUTE u7=999.  
IF (d7=2) u7 = 15.1.  
IF (d7=1) u7 = 15.1.
```

IF (d7=0) u7 =0.

COMPUTE i1=0.

IF (d3=2 AND d7=2) i1=6.6.

COMPUTE CarerQolTariff=u1+u2+u3+u4+u5+u6+u7+i1.

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