



Learning from integrated eCare practice and
promoting deployment in European regions

D6.1 EVALUATION FRAMEWORK

WP6 Pilot evaluation

Version 1.2, 18th December 2014

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Document information

Abstract

This document contains the scientific protocol for the BeyondSilos project.

Organisation responsible

Region of Southern Denmark (RSD)

Authors

Daugbjerg, Signe (RSD)

Da Col, Paolo (HIM)

Contributing partners

Ciccarelli, Michele (Campania)

Faubel, Raquel (LAFE)

Fernandes, Adriano (Amadora)

Georgieva, Lidia (CPRH)

Goncalves, Rute (Amadora)

Hobson, Penny (HSCNI)

Hurtado, Mayte (HIM)

Iaccarino, Guido (Campania)

Lewis, Leo (HIM)

Melle, Christian (Kinzigital)

Meyer, Ingo (Emperica)

Müller, Sonja (Emperica)

Piera, Jordi (BSA)

Oates, John (HIM)

Roth, Monica (Kinzigital)

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Outstanding issues

Parts of the evaluation framework will need further updating as data collection is finalised.

Filename

D6.1 v1.2 BeyondSilos Evaluation framework

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This deliverable contains original unpublished work except where clearly indicated otherwise.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.

Executive summary

Deliverable D6.1 is the scientific protocol for the BeyondSilos project. The protocol presents descriptions of the relevant information for carrying out an evaluation of ICT supported integrated health and social care.

The protocol is based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement [1]. It presents the background of the evaluation, objectives, methodologies used for selection of participants, data collection, data management, statistics, monitoring and ethics. The protocol describes the evaluations of the new pilot sites organisational models along with the overall evaluation of BeyondSilos project.

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1 Introduction

1.1 Purpose of this document

WP6 for BeyondSilos includes detailing and finalising the methodology for the pilot evaluation. This scientific protocol will ensure that the evaluation data collection during the delivery of integrated health and social care (both in the comparison phase and the new care phase) is carried out according to a common methodology across all pilot sites.

BeyondSilos is collaborating closely with two other projects, CareWell and SmartCare. The three projects strive to create synergy and coherence between the methodologies used in the evaluation framework for the projects to allow comparison of results between the three projects.

However, the three projects are different, and the evaluation framework is adapted to the specific needs of each of them. Moreover, the evaluation of each project will be performed independently from the other two projects, but ensuring that the lessons learned within each project will be transferred to the others.

This evaluation framework constitutes D6.1. Throughout the text, when referring to the current document, it will be termed a protocol as opposed to an evaluation framework. The document will be reissued as further details are agreed.

1.2 Structure of document

The following issues will be covered in the protocol:

- Section 2 provides background information, the rationale and the objectives of the project.
- Section 3 describes the methodology including the study design, the setting, the participants, the eligibility criteria, the variables, the indicators and comparators, and the statistical methods.
- Section 4 covers approvals from ethical committees, authorship guidelines including scientific dissemination strategy.

1.3 Glossary

Abbreviation	Full name
ACG	Adjusted Clinical Groups
ANOVA	Analysis of variance
CCI	Charlson Comorbidity Index
CHF	Chronic Heart Failure
CI	Confidence Intervals
COPD	Chronic Obstructive Pulmonary Disease
CRF	Case Report Form
CV	Curriculum Vitae
DES	Discrete Event Simulation
EHR	Electronic Healthcare Record
EPR	Electronic Patient Records

Abbreviation	Full name
EU	European Union
GP	General Practitioner
HADS	Hospital anxiety and depression scale
HTA	Health Technology Assessment
IC	Integrated Care
ICD9	International Classification of Disease, 9 th edition,
ICT	Information Communication Technology
IHC	Integrated Health Care
ISPOR	The International Society for Pharmacoeconomics and Outcomes Research
MAST	Model for ASsessment of Telemedicine applications
NHS	National Health Service
OR	Odds Ration
PhD	Academic Degree of Doctor of Philosophy
PSP	Policy Support Programme
Renewing Health	REgioNs of Europe WorkINg toGether for HEALTH
STROBE	Strengthening the Reporting of Observational studies in Epidemiology
TM	Telemedicine
WHO	World Health Organisation
WP	Work Package

2 Background and rationale

The protocol will evaluate the impact of the new organisational models developed in the framework of the BeyondSilos pilot service in order to provide ICT supported integrated health and social care to elderly patients. The evaluation will be performed covering the needs of the different principal stakeholders, such as end users (care recipients), informal carers, formal care staff / professionals, managers, decision-makers and third-party payers. Evaluation of integrated health and social care service delivery processes (process evaluation) will improve the current scientifically based knowledge base on barriers and facilitators towards integrated care (IC) delivery. Beyond this, scientific knowledge will be generated on outcomes of IC service delivery from the perspective of all actors involved. Apart from generating a number of self-standing deliverables, this work package will directly feed into WP7 with a view to support further exploitation of project outcomes beyond the end of the project by relevant stakeholders, and wider dissemination during the project.

2.1 Main hypothesis

Integrated care will lead to a more personalised and coordinated care, improve outcomes for elderly patients, deliver more effective care and support, and provide more cost efficient health and social services.

2.2 Objectives

The overall aim of the evaluation carried out in BeyondSilos is to identify the differences introduced by implementing ICT supported integrated care in different domains according to the MAST evaluation framework [2], including safety, clinical and social outcomes, resource use and cost of care, user/carer experience and organisational changes. The focus of the evaluation will be the impact of so called “horizontal” integration, which is the integration between social care and health care, and the changing organisational models for elderly patients.

3 Methods

The evaluation will be conducted using the MAST multi-dimensional evaluation methodology adapted to the needs of the BeyondSilos project, focusing on ICT supported integrated care, in accordance with the recommendations of the ISPOR Good Research Practice Task Force on Prospective Observational Studies [3] and the STROBE statement [1].

MAST is based on Health Technology Assessment (HTA), and has been successfully validated in the ICT PSP Type A project Renewing Health. It is encountering an increasing level of success among organisations involved in trials of complex interventions such as those piloted in United4Health, SmartCare and CareWell, because it fills a gap which has been widely felt in this area.

MAST was developed under contract with the European Commission (MethoTelemed project) by a multinational team led by the Odense University Hospital, which is participating in United4Health as part of the South Denmark Regional Partnership. The same team, which developed and validated MAST, will be in charge of the evaluation of BeyondSilos. MAST includes assessment of the outcomes of telemedicine applications divided into the following seven domains:

- 1) Health problem and characteristics of the application.
- 2) Safety.
- 3) Clinical effectiveness.
- 4) Patient perspectives.
- 5) Economic aspects.
- 6) Organisational aspects.
- 7) Socio-cultural, ethical and legal aspects.

For further description of the MAST domains, please see Kidholm et al 2012 [2].

As part of the evaluation, BeyondSilos will address the economic aspects of the new services. The economic evaluation will be carried out as part of Work Package 7, comprising the exploitation and business model development work. Further details on the methodological approach will be reported in D7.1.

3.1 Study design

The aim of the evaluation is to quantify the relationship between ICT supported integrated care services to elderly patients and specific outcomes eight months after the deployment of the new organisational models. The most appropriate study design for the evaluation is the cohort-study (prospective observational study), given that random allocation is not possible.

The strengths of this study design are mainly the collection of real-life data about impact on effectiveness, costs and organisation (structure, processes, and outcomes) which allows the identification of barriers and facilitators for a wider service implementation. Furthermore, the long follow-up period allows for registering and monitoring long-term health effects and other outcomes, while the large sample size allows for stratification analysis and identification of patient subgroups that benefit most from the intervention.

In addition, from an ethical perspective, if the new care is proved effective, it should be offered to all potential users in need of integrated health and social care. This type of study design will assess the real-life effectiveness of the trialled services with a high degree of external validity and generalisability of the results. Due to inclusion of patients from many European countries, this study will be able to provide a valid estimate of the expected impact of the new organisational models in other regions of Europe.

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3.2 Setting

All settings that are in any way relevant to the provision of health and social care are included. Therefore, out-of-hospital (community) services as well as hospitals, GPs' offices, community nurses, and any type of care practitioners, users' homes and volunteer service providers' offices will be engaged. Participants will be enrolled and the evaluation will be conducted at the following seven pilot sites.

- Northern Ireland
- Badalona
- Valencia
- Campania
- Amadora
- Kinzigital
- Sofia

3.2.1 Dates and timetable

The enrolment will start on 1st September 2014 and will end 31st Marts 2015. In the enrolment period, the pilot sites will be expected to achieve the sample size they have declared and quoted in the Technical Annex. Any deviation from the declared number has to be reported with a proper explanation to the evaluation work package leader (WP6) and to the Pilot site preparation and operation leader (WP5). Early dropouts (within the first four months) should be replaced. The maximum duration of the follow-up will be eight months, while the minimum will be six months. Data collection has to be completed and all data has to be uploaded to the central web-database before 30th June 2016, and the evaluation completed before 31st December 2016.

Table 1: Timetable

	Case finding Start	Case finding end	Finish data collection and upload all data to central web-database	Data source for comparator group
Northern Ireland	1 st December 2014	1 st August 2015	30 th June 2016	Parallel comparison groups
Badalona	1 st December 2014	1 st February 2015	30 th June 2016	Parallel comparison groups
Valencia	Ongoing	1 st March 2015	30 th June 2016	Parallel comparison groups
Campania	1 st September 2014	1 st September 2015	30 th June 2016	Parallel comparison groups
Amadora	1 st September 2014	All cases have been identified	30 th June 2016	Six month of comparison collection (usual care) followed by 8 month of new care
Kinzigital	1 st December 2014	1 st March 2015	30 th June 2016	Parallel comparison groups
Sofia	1 st February 2015	1 st February 2015	30 th June 2016	Parallel comparison groups

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3.2.2 Data collection and management

A case report form (CRF), including a codebook, will be developed in Excel describing all the specific data that the pilot sites will have to collect from the participants and study settings. The codebook will specify level of variables, type of data (text or numbers), as well as validation rules, including minimum and maximum values. Each pilot site will be responsible for collecting their own data, and to cleaning data in line with the evaluation protocol (see section 3.9 Data handling) De-identified data from each pilot site will be uploaded to a central web-based database administered by Region of Southern Denmark. This will allow comparison of data between the different pilot sites. Each pilot site will have a separate log-in to access the database, and will be able to view its own data as well as aggregated data from all the pilot sites. The database will have daily back-up and secured data transfer. Internet connection is mandatory in order to access the central web-based database. The pilot sites are responsible for ongoing upload of collected data to the central web-database during the evaluation period. The deadline for data upload to the central web-database will be first week of each month starting at enrolment.

3.3 Study population

3.3.1 Eligibility criteria

Inclusion criteria for end users:

Participants eligible for the evaluation must comply with all of the following criteria:

- Age ≥65 years.
- Presence of health needs specified as:
 - Presence of heart failure, stroke, COPD or diabetes (diagnosed at hospital or at specialist visit) plus at least one additional chronic disease / condition included in the Charlson Comorbidity Index (CCI) [4].
- Presence of social needs based on Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL).
- Reasonable expectation of permanence in the BeyondSilos project for the whole data collection period (18 months).
- Informed consent, signed if necessary (by the subject or his/her delegate).
- Capability to handle ICT equipment / devices alone, or with the help from a delegate.
- Presence of good/reliable communication connection at home (internet, telephone or what is needed for the ICT connection).

Exclusion criteria for end users:

- Subjects who have been registered with an active cancer diagnosis and undergoing treatment, has undergone an organ transplant, or is undergoing dialysis prior to enrolment.
- Subjects in a terminal state.
- People with an AIDS diagnose

3.3.2 Recruitment of study population

The set-up of all BeyondSilos pilot sites is cohort studies, which means that a group of people with similar characteristics will be followed over a period of time. In order to measure whether integrated health and social care has an effect, all pilot sites will provide both a group that will receive the new care and a comparator group that receives usual care. Potential participants are selected by screening electronic

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healthcare and social care records or/and the hospital / national databases and/or during long term condition annual reviews in the community setting. If necessary, candidates are informed about the nature and the objectives of the evaluation. If a candidate passes the inclusion/exclusion criteria and signs the informed consent form, if necessary, they participate in the evaluation. Figure 1 summarises the flow of enrolment to clarify the steps of recruiting patients.

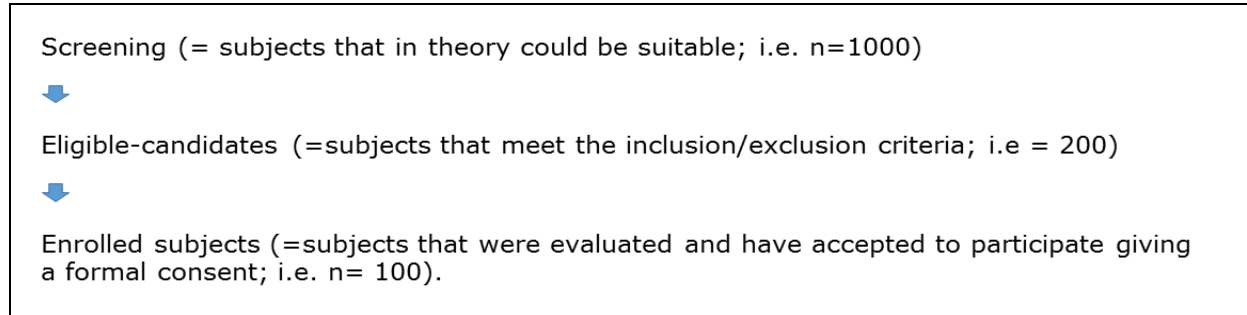


Figure 1: Steps for the recruitment

It is relevant to underline three key issues in the recruitment of the study population:

- Deadlines for enrolment and follow-up period have to be followed (see section 3.2.1).
- The pilot sites are expected to replace early drop-outs; therefore there will be continuous attention to eligible candidates (thus maintaining the screening phase active).
- The recruitment can be performed by both healthcare practitioners and by social care professionals, who will be qualified to reach this goal.

3.3.3 Comparator group

To take appropriate account of particular national/regional circumstances the rules for selecting a comparator group can differ between pilot sites. Most pilot sites will have a parallel running comparator group that receives usual care (option 1, Figure 2). However, one pilot sites has decided to enrol subjects in a two phase-observation period, where phase 1 is the comparator phase (usual care), and phase 2 is the new care phase (option 2, Figure 3).

Option 1: All subjects to be enrolled ($n = 100$) will be assigned to one of the two groups. Both groups will be followed in parallel over time.

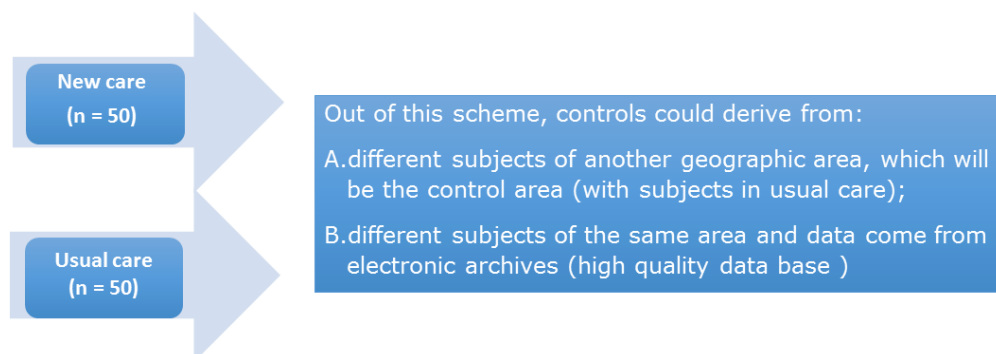


Figure 2: Composition of the comparator group - Option 1 parallel group

Option 2: All enrolled subjects ($n = 100$) enter into a two phases-observation period of 18 months, where phase I is the comparator phase (usual care) and phase II is the new care phase.

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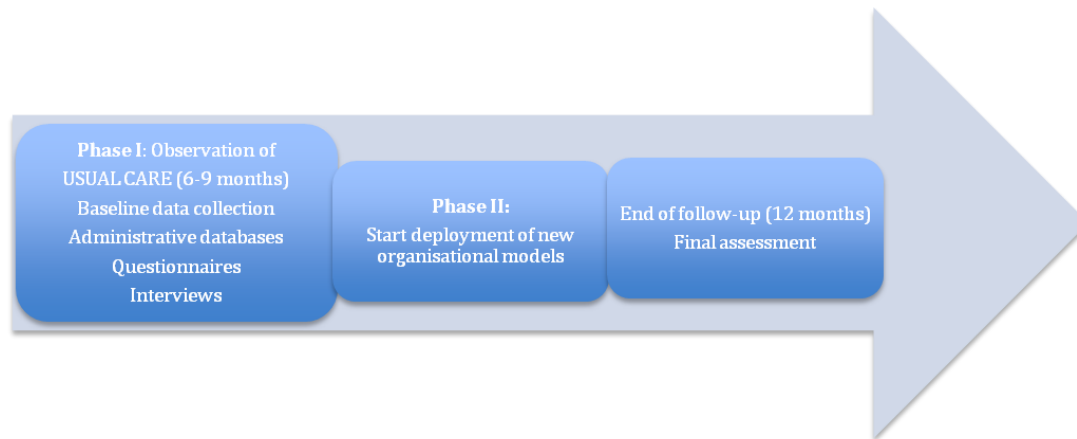


Figure 3: Composition of the comparator group - Option 2 phased group

3.4 Variables

All outcome measures, format of variables, timing and preferred collection method were fully discussed and agreed with the deployment sites. These are presented in **Error! Reference source not found.** below. The table indicates whether each variable will be collected on a voluntary (V) or mandatory (M) basis. The mandatory variables are defined by study aims and objectives, and will be used in the final analyses of the study.

The final indicator list was approved at the PCC meeting held in Lisbon, Portugal, on 16th-17th October, 2014. The mandatory questionnaires are included in Appendix A.

The variables / indicators of interest cover the following domains:

1. Overall service effectiveness and specific outcome metrics:
 - 1.a Disease specific health status metrics.
 - 1.b Generic health related / functional quality of life.
 - 1.c Psychological metrics.
2. Safety.
3. End user / client / carer perspectives.
4. Economic measures.
5. Organisational impact measures.
6. Possible confounders / control variables.

Table 2: Outcome, metrics, timing and preferred collection method

Table 2.1: Overall service effectiveness and specific outcome measures

Hospital				
Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Admission ¹	Date	M	Historical data and during follow-up	Databases
Discharge ²	Date	M	Historical data and during follow-up	Databases

Hospital				
Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Duration³ (calculate from admission date and discharge date)	Days	M	Historical data and during follow-up	Databases
Indication for hospitalisation	ICD10 code	M	Historical data and during follow-up	Databases
Re-hospitalisation within 30 days (calculate from admission date and discharge date)	ICD10 code	M	Historical data and during follow-up	Databases
Origin⁴	Categorical	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Discharge destiny⁵	Categorical	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire

Notes:

¹ Admission date to hospital,² discharge from hospital,³ length of the hospital stay,⁴ indicates who initiated the contact,⁵ describes the outcome of the contact

GP, Specialists, Nurse, other healthcare providers				
Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Physical meeting at Health centre/office	Date	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Home visits	Date	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Telephone	Date	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Writing (e-mail, SMS, etc.)	Date	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Origin¹	Categorical	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Discharge destiny²	Categorical	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire

Notes:

¹ indicates who initiated the contact,² describes the outcome of the contact

Social care & Voluntary sector				
Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Physical meeting at social centre / office	Date	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Home visits	Date	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Telephone	Date	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Writing (e-mail, SMS, etc.)	Date	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Origin ¹	Categorical	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire
Discharge destiny ²	Categorical	M if possible and relevant for pilot	Historical data and during follow-up	Databases / questionnaire

Notes:

¹ indicates who initiated the contact,

² describes the outcome of the contact

Table 2.2a: Disease specific health status measurement

Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Weight	Kilo gram (kg)	M	Baseline / end	Databases / questionnaire
Height	Centimetre (cm)	M	Baseline / end	Databases / questionnaire
Blood pressure	mmHg	M if relevant for pilot	Baseline / end	Databases / questionnaire
Heart rate	bpm	M if relevant for pilot	Baseline / end	Databases / questionnaire
Stroke Severity	Scale	M if relevant for pilot	Baseline / end	Databases / questionnaire
NYHA Classification	Scale	M if relevant for pilot	Baseline / end	Databases / questionnaire
Oxygen saturation	%	M if relevant for pilot	Baseline / end	Databases / questionnaire
Blood glucose	mg/dl	M if relevant for pilot	Baseline / end	Databases / questionnaire
HbA1c	%	M if relevant for pilot	Baseline / end	Databases / questionnaire
Creatinine	mg/dl	M if relevant for pilot	Baseline / end	Databases / questionnaire

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Table 2.2b: Generic health related / functional quality of life

Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Charlson Comorbidity Index (CCI)	ICD-10-CM AND Scale	M	Baseline / end	Databases / questionnaire
Barthel index	Scale	M	Baseline / end	Databases / questionnaire
Self-maintaining and instrumental activities of daily living (IADL)	Scale	M	Baseline / end	Databases / questionnaire

Table 2.2c: Psychological measures

Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
GDS - Geriatric Depression Scale (Short Form)	Scale	M	Baseline / midterm / end	Databases / questionnaire
Anxiety and depression according to HADS	Scale	V	Baseline / midterm / end	Databases / questionnaire

Table 2.3: User perspectives

Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
PIRU questionnaire on user experience of IC (selected questions)	Scale for each question	M	Baseline / midterm / end	Questionnaire
End user perception of service utility according to eCCIS (selected questions)	Scale for each question	M	Baseline / midterm / end	Questionnaire
Carer perception of service utility according to eCCIS	Scale for each question	V	Baseline / midterm / end	Questionnaire
NHS LTC6 template	Scale for each question	V	Baseline / midterm / end	Questionnaire

Table 2.4: Economic aspects

Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Efforts related to service development & implementation	Number	M	Exit, Implementation and pilot phase	Databases / questionnaire / interviews
Efforts related to service operation or use	Number	M	Exit, Implementation and pilot phase	Databases / questionnaire / interviews
Equipment cost	Number	M	Exit, Implementation and pilot phase	Databases / questionnaire / interviews

Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Service effectiveness benefits	Number	M	Exit, Implementation and pilot phase	Databases / questionnaire / interviews
Service efficiency benefits	Number	M	Exit, Implementation and pilot phase	Databases / questionnaire / interviews
Revenue streams	Number	M	Exit, Implementation and pilot phase	Databases / questionnaire / interviews
Willingness to pay	Scale	V	Exit, Implementation and pilot phase	Databases / questionnaire / interviews

Table 2.5: Organisational aspects

Organisational aspects are mostly covered by qualitative data collections. A dedicated protocol at WP level is being developed in cooperation with WP2 Organisational Models and Service Process Models and WP6 Pilot Evaluation. It will be mandatory to have an organisational data collection. However, the majority of the questions will be voluntary, since they will depend on the local context and the technology being implemented. The table below includes the aspects that should be covered in the organisational data collection.

Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Impacts on staff	Scales, qualitative	M	End	Questionnaire / interviews
Impacts on organisations	Scales, qualitative	M	End	Questionnaire / interviews
Service integration aspects	Scales, qualitative	M	End	Questionnaire / interviews
Mainstreaming potential and sustainability	Scales, qualitative	M	End	Questionnaire / interviews

Table 2.6: Possible confounders and baseline data

Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Year of birth	Date	M	Baseline	Databases / questionnaire / interviews
Gender	Binary	M	Baseline	Databases / questionnaire / interviews
Level of education	Categorical	M	Baseline	Databases / questionnaire / interviews
Marital status	Categorical	M	Baseline	Databases / questionnaire / interviews
Ethnicity	Categorical	V	Baseline	Databases / questionnaire / interviews

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Measure	Variable format	Mandatory / voluntary	Timing of measurement	Preferred collection method
Longest held occupation	Categorical	M	Baseline	Databases / questionnaire / interviews
Housing tenure	Categorical	M	Baseline	Databases / questionnaire / interviews
People older than 18 living in household	Categorical	M	Baseline	Databases / questionnaire / interviews
Household income (yearly)	Categorical	V	Baseline	Databases / questionnaire / interviews
Tobacco use	Continuous	M	Baseline	Databases / questionnaire / interviews
Alcohol consumption	Continuous	M	Baseline	Databases / questionnaire / interviews
Mobile phone use	Binary	M	Baseline	Databases / questionnaire / interviews
PC / laptop use	Binary	M	Baseline	Databases / questionnaire / interviews

3.5 Data source/measurement

See section 3.4 **Error! Reference source not found..**

3.6 Bias

Some methodological issues should be considered when planning the evaluation, data collection and the analyses for the BeyondSilos project.

3.6.1 Information bias

Data will be collected from different sources, which includes administrative databases, questionnaires and interviews. Missing or inaccurate reporting in the administrative databases might occur. Therefore, each pilot site has to provide information on the quality of the databases used to collect information in order to assess the quality of the data. Missing or inaccurate information from the administrative databases are not expected to depend on the implementation of the ICT supported integrated healthcare (the exposure). Therefore, this possible non-differential misclassification should only have minor effect on the analyses.

Information collected from questionnaires and interviews may be influenced by recall bias. One pilot site has to collect data directly from the subjects for some of the primary outcomes, such as prior hospitalisations and contacts with healthcare services, and therefore may be especially effected by this form of bias. The magnitude of the effect of the bias on the study's result will be assessed and discussed in the analysis phase.

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3.6.2 Selection bias

Differences in characteristics between subjects who consent to participate in the BeyondSilos project and those who decline may affect the external validity of the results of the new care. In order to address this issue, demographic characteristics of the included subjects will be compared with those who decline in order to examine for any systematic differences.

Pilot sites that are planning to enrol subjects in a two phase-observation period have to be aware of potential bias due to seasonal changes in the outcome measures. As an example, it is well established that more hospitalisations occurs in the winter period compared to the summer period, especially in the elderly population. It is therefore important that the pilot sites consider the seasonal calendar related effect when planning their comparison period.

3.7 Sample size

The number of patients which will be recruited and included in the evaluation of the project is:

- Pilot 1 - Northern Ireland: 490 new care – 490 usual care
- Pilot 2 – Badalona: 100 new care – 100 usual care
- Pilot 3 – Valencia: 100 new care – 100 usual care
- Pilot 4 - Campania: 50-100 new care – 50-100 usual care
- Pilot 5 - Amadora: 150 each in usual and subsequently in new care
- Pilot 6 - Kinzigtal: 50 new care – 50 usual care
- Pilot 7 - Sofia: 50 new care – 50 usual care

In total, more than 2200 patients will be included in the evaluation of the project.

3.8 Statistical methods

Separately analyses will be performed for each pilot site, as well as some common analyses comparing the results between the pilot sites for primary outcomes and for some selected secondary outcomes.

3.8.1 Local pilot sites

The choice of method to analyse the data depends on:

- the type of data that are investigated (dichotomous, categorical or numerical);
- whether or not the data are normally distributed.

Simple comparisons of the distribution of data will be performed and presented in tables or histograms.

Depending on the distribution of the data, continuous outcome variables are planned to be analysed using multivariate ANOVA tests examining the difference between group means.

Binary outcome variables will be analysed using multiple logistic regression models estimating the Odds Ratio (OR) with proper confidence intervals (CI). Different models adjusting for age, sex and other possible confounding variables will be performed.

A final detailed strategy for analyses will be elaborated before analysing data.

3.8.2 Overall analyses

Meta-analyses are planned to be used to summarise and compare the results for the primary and secondary outcomes for the different pilot sites. The results from the meta-analyses will be presented as

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tables along with graphs showing the forest plots. In order to assess the percentage of the total variation in estimated effects across the studies that is due to heterogeneity rather than to chance, the I^2 will be shown for all meta-analyses.

First, a meta-analysis including results from all the pilot sites will be performed for the primary outcome, and investigated for subgroup impacts based on similarities among populations. The relevance of this analysis will be discussed based on the level of heterogeneity presented in the meta-analysis. Next, the pilot sites that have similar populations in terms of disease, frailty or other factors will be analysed together in a meta-analysis.

A final detailed strategy for the meta-analyses will be elaborated before analysing data.

3.9 Data handling

A two step procedure will be performed in order to detect and handle errors in the data that might impact the study results:

- Step 1: All pilot sites have to perform the following data cleansing process before submitting the data to the central web-based database. All subjects with missing values, or values that are considered to be illegal or outliers, must be checked and compared to an alternative reliable data source if such is available. The correct value (the most plausible) should be included in the dataset. However, a note must be made about the alteration of the value.
- Step 2: The following data cleansing will be performed when the data has been collected in the central web-based database before performing the analyses.

Missing values

- If one subject has <50% missing values, the remaining values are allowed in analyses.
- Analyses that require some of the missing data will be run without the values, and reporting will present the total number of subjects in all analyses.

Outlier

- If a value is considered to be a realistic outlier, the value will remain unchanged. Sensitivity analysis will be carried out to assess the impact of the outliers.
- If a value is considered to be an unrealistic outlier, the value will be re-coded as missing.

Range check

- A value is considered illegal if it falls outside the min-max range of possible values, and will be re-coded as missing.

Categorical variables

- All observations must relate to the predefined categories, otherwise the value will be registered as missing.

4 Ethics and dissemination

4.1 Plans for seeking research approval

Whenever necessary, pilot sites will seek ethical approval in order to collect and evaluate patient data.

4.2 Authorship guidelines

Regarding scientific dissemination, the BeyondSilos project will agree on a process for authorship, acknowledgment of the project work and other supportive works, and sign off. This process will be mandatory for all publications conducted in the context of the BeyondSilos project or its data. The process for authorship will be decided at the next PCC meeting, and included in an updated version of the evaluation protocol.

5 Conclusion

This protocol contains the suggested evaluation framework for the BeyondSilos project, reviewed and agreed by the BeyondSilos evaluation group. The content of the protocol was finally approved at the PCC meeting held in Lisbon, Portugal, on 16th-17th October, 2014. Parts of the evaluation framework will need further updating as data collection is finalised. Additional conclusions will be added parallel with the data collection and analyses.

6 References

1. Vandenbroucke JP, Elm E von, Altman DG, et al. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Explanation and Elaboration. *Epidemiology* 2007;18: 805–835.
2. Kidholm K , Ekeland AG, Jensen LK, Rasmussen J, Pedersen CD, Bowes A, Flottorp SA, Bech M. A model for assessment of telemedicine applications: MAST. *International Journal of Technology Assessment in Health Care* 2012; 28 (1) 44-51.
3. Berger ML, Dreyer N, Anderson Fred, et al. Prospective Observational Studies to Assess Comparative Effectiveness: The ISPOR Good Research Practices Task Force Report. *Value Health* 2012;15:217-230.
4. Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Diseases*, 40(5), 373–383.

Appendix A – Questionnaires

The following questionnaires will be used in the evaluation process:

- Q1: Charlson comorbidity index (CCI)
- Q2: Barthel Index
 - Barthel Index of Activities of Daily Living (Scores Range 0 – 100)
 - (Scores Range 0 – 20)
- Q3: Instrumental Activities of Daily Living Scale (IADL)
- Q4: Geriatric Depression Scale (Short Form)
- Q5: PIRU questionnaire on user experience of Integrated Care
- Q6. eCCIS – eCare Client Impact Survey

They are presented in the following sections

A.1 Q1: Charlson comorbidity index (CCI)

The Charlson Comorbidity Index contains 19 categories of comorbidity, which are primarily defined using ICD-9-CM diagnoses codes. Each category has an associated weight, taken from the original Charlson paper¹, which is based on the adjusted risk of one-year mortality. The overall comorbidity score reflects the cumulative increased likelihood of one-year mortality; the higher the score, the more severe the burden of comorbidity.

Work by Quan et al. (2005)² has modified the Charlson Comorbidity Index (ICD-9-CM codes) and updated the coding to ICD-10. These updates are presented towards the end of this concept with the corresponding ICD-10 codes. In the appendix, you can also find the coding algorithms of Quan et al. (2005) for defining comorbidities in ICD-9-CM and ICD-10 administrative data.

The Index may be calculated either for a single record (separation) or over a defined period of time prior to an index event. Every diagnosis and procedure code is analysed to see if it falls within one of the 16 comorbid conditions. If one of these is found, a flag for that condition is set. These flags are weighted appropriately and summed to generate values. There are available SAS macros (e.g. MCHP SAS macro code) that will compute the Index.

In order, to estimate the CCI, the Comorbidity Score has to be added to Age Score and the total denoted as “i” below.

¹ Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis 1987;40(5):373-383.

² Quan H, Sundararajan V, Halfon P, Fong A, Burnand B, Luthi JC, Saunders LD, Beck CA, Feasby TE, Ghali WA. Coding algorithms for defining comorbidities in ICD-9-CM and ICD-10 administrative data. Med Care 2005;43(11):1130-1139.

D6.1 Evaluation framework

A.1.1 Coding algorithms for defining comorbidities in ICD-9-CM and ICD-10 administrative data

Comorbidities	Deyo's ICD-9-CM	ICD-10	Enhanced ICD-9-CM
Myocardial infarction	410.x, 412.x	I21.x, I22.x, I25.2	410.x, 412.x
Congestive heart failure	428.x	I09.9, I11.0, I13.0, I13.2, I25.5, I42.0, I42.5-I42.9, I43.x, I50.x, P29.0	398.91, 402.01, 402.11, 402.91, 404.01, 404.03, 404.11, 404.13, 404.91, 404.93, 425.4-425.9, 428.x
Peripheral vascular disease	443.9, 441.x, 785.4, V43.4 Procedure 38.48	I70.x, I71.x, I73.1, I73.8, I73.9, I77.1, I79.0, I79.2, K55.1, K55.8, K55.9, Z95.8, Z95.9	093.0, 437.3, 440.x, 441.x, 443.1-443.9, 47.1, 557.1, 557.9, V43.4
Cerebrovascular disease	430.x-438.x	G45.x, G46.x, H34.0, I60.x-I69.x	362.34, 430.x-438.x
Dementia	290.x	F00.x-F03.x, F05.1, G30.x, G31.1	290.x, 294.1, 331.2
Chronic pulmonary disease	490.x-505.x, 506.4	I27.8, I27.9, J40.x-J47.x, J60.x-J67.x, J68.4, J70.1, J70.3	416.8, 416.9, 490.x-505.x, 506.4, 508.1, 508.8
Rheumatic disease	710.0, 710.1, 710.4, 714.0-714.2, 714.81, 725.x	M05.x, M06.x, M31.5, M32.x-M34.x, M35.1, M35.3, M36.0	446.5, 710.0-710.4, 714.0-714.2, 714.8, 725.x
Peptic ulcer disease	531.x-534.x	K25.x-K28.x	531.x-534.x
Mild liver disease	571.2, 571.4-571.6	B18.x, K70.0-K70.3, K70.9, K71.3-K71.5, K71.7, K73.x, K74.x, K76.0, K76.2-K76.4, K76.8, K76.9, Z94.4	070.22, 070.23, 070.32, 070.33, 070.44, 070.54, 070.6, 070.9, 570.x, 571.x, 573.3, 573.4, 573.8, 573.9, V42.7
Diabetes without chronic complication	250.0-250.3, 250.7	E10.0, E10.1, E10.6, E10.8, E10.9, E11.0, E11.1, E11.6, E11.8, E11.9, E12.0, E12.1, E12.6, E12.8, E12.9, E13.0, E13.1, E13.6, E13.8, E13.9, E14.0, E14.1, E14.6, E14.8, E14.9	250.0-250.3, 250.8, 250.9
Diabetes with chronic complication	250.4-250.6	E10.2-E10.5, E10.7, E11.2-E11.5, E11.7, E12.2-E12.5, E12.7, E13.2-E13.5, E13.7, E14.2-E14.5, E14.7	250.4-250.7
Hemiplegia or paraplegia	344.1, 342.x	G04.1, G11.4, G80.1, G80.2, G81.x, G82.x, G83.0-G83.4, G83.9	334.1, 342.x, 343.x, 344.0-344.6, 344.9
Renal disease	582.x, 583-583.7, 585.x, 586.x, 588.x	I12.0, I13.1, N03.2-N03.7, N05.2-N05.7, N18.x, N19.x, N25.0, Z49.0-Z49.2, Z94.0, Z99.2	403.01, 403.11, 403.91, 404.02, 404.03, 404.12, 404.13, 404.92, 404.93, 582.x, 583.0-583.7, 585.x, 586.x, 588.0, V42.0, V45.1, V56.x
Any malignancy, including lymphoma and leukemia, except malignant neoplasm of skin	140.x-172.x, 174.x-195.8, 200.x-208.x	C00.x-C26.x, C30.x-C34.x, C37.x-C41.x, C43.x, C45.x-C58.x, C60.x-C76.x, C81.x-C85.x, C88.x, C90.x-C97.x	140.x-172.x, 174.x-195.8, 200.x-208.x, 238.6
Moderate or severe liver disease	456.0-456.21, 572.2-572.8	I85.0, I85.9, I86.4, I98.2, K70.4, K71.1, K72.1, K72.9, K76.5, K76.6, K76.7	456.0-456.2, 572.2-572.8
Metastatic solid tumor	196.x-199.1	C77.x-C80.x	196.x-199.x
AIDS/HIV	042.x-044.x	B20.x-B22.x, B24.x	042.x-044.x

A.1.2 Comorbidity Score: weighting of the clinical conditions and corresponding ICD-10 codes

Weights	Clinical conditions	ICD-10 codes
1	Myocardial infarct	I21.x-I23.x, I25.2
	Congestive heart failure	I09.9, I11.0, I13.0, I13.2, I25.5, I42.0, I42.5-I42.9, I43.x, I50.x, P29.0
	Peripheral vascular disease	I70.x-I74.x, I77.x, I79.0, I79.2, K55.1, K55.8, K55.9, Z95.8, Z95.9
	Dementia	F00.x-F03.x, F05.1, G30.x, G31.1
	Cerebrovascular disease	G45.x-G46.x, H34.0, I60.x-I69.x
	Chronic lung disease	I27.8-I27.9, J40.x-J47.x, J60.x-J67.x, J68.4, J70.1, J70.3, J84.1; J92.0; J96.1; J98.2; J98.3
	Connective tissue disease	M05.x, M06.x, M08.x, M09.x, M30.x-M36.x, D86.x
	Ulcer	K22.1, K25.x-K28.x

D6.1 Evaluation framework

Weights	Clinical conditions	ICD-10 codes
	Chronic liver disease	B18.x, K70.0-K70.3, K70.9, K71.x, K73.x-K74.x, K76.0, K76.2-K76.4, K76.8, K76.9, Z94.4
2	Hemiplegia	G04.1, G11.4, G80.1, G80.2, G81.x, G82.x, G83.0 to G83.4, G83.9
	Moderate or severe kidney disease	I12.x, I13.1, N00.x-N05.x, N07.x, N11.x, N14.x, N17.x-N19.x, N25.x, Q61.x, Z49.0 to Z49.2, Z94.0, Z99.2
	Diabetes	E10.0, E10.1, E10.9, E11.0, E11.1, E11.9, E12.0, E12.1, E12.6, E12.8, E12.9, E13.0, E13.1, E13.6, E13.8, E13.9, E14.0, E14.1, E14.6, E14.8, E14.9
	Diabetes with complication	E10.2-E10.8, E11.2-E11.8, E12.2-E12.5, E12.7, E13.2-E13.5, E13.7, E14.2-E14.5, E14.7
	Tumor	C00.x-C76.x, C86.x-C87.x, C97.x
	Leukemia	C91.x-C95.x
	Lymphoma	C81.x-C85.x; C88x; C90.x; C96.x
3	Moderate or severe liver disease	B15.0, B16.0, B16.2, B19.0; I85.x, I86.4, I98.2, K70.4, K71.1, K72.x, K72.9, K76.5, K76.6, K76.7
6	Malignant tumor/metastasis	C77.x-C80.x
	AIDS	B20.x-B24.x

Age Score

- Age <50 years: 0 points
- Age 50-59 years: 1 points
- Age 60-69 years: 2 points
- Age 70-79 years: 3 points

There is also the option of calculating the Charlson Probability (10 year mortality) where Z is the 10 year survival:

- Calculate $Y = e^{(i * 0.9)}$
- Calculate $Z = 0.983^Y$

However, one major issue using CCI is that in several European countries there are legal restrictions concerning AIDS; e.g. the Italian law does not allow to ask, collect or keep data relevant to AIDS, and so although AIDS is not very often in our target population, the calculated index may underestimate the real severity of comorbidities.

A.2 Q2: Barthel index (BI)

The Barthel Index (BI) was developed as a measure to assess disability in patients with neuromuscular and musculoskeletal conditions receiving inpatient rehabilitation [1] and has been recommended by the Royal College of Physicians in the UK for routine use in the assessment of older people [2]. The index is an ordinal scale comprising ten activities of daily living. The original BI was scored in steps of five points to give a maximum total score of 100 (Appendix A.2.1). A widely adopted modification to the index by Collin and Wade [3] includes a revised score range of 0–20 (Appendix A.2.2)³. Items are rated based on the amount of assistance required to complete each activity. Information can be obtained from the patient's self-report, from a separate party who is familiar with the patient's abilities (such as a relative), or from observation. Lower scores indicating increased disability.

³ References:

- [1] Mahoney FI, Barthel DW. Functional Evaluation: The Barthel Index. *Maryland State Med J* 1965; 14: 61–5
- [2] Report of joint workshops of the Research Unit of the Royal College of Physicians and the British Geriatrics Society. Standardised assessment scales for elderly people. London: Royal College of Physicians 1992
- [3] Collin C, Wade D. The Barthel Index: a reliability study. *Int Disabil Stud* 1988; 10: 61–3

D6.1 Evaluation framework

A.2.1 Barthel Index of Activities of Daily Living (scores range 0 – 100)

(Ref: Mahoney FI, Barthel D. "Functional evaluation: the Barthel Index." Maryland State Medical Journal 1965;14:56-61)

Activity	Score
FEEDING 0 = unable 5 = needs help cutting, spreading butter, etc., or requires modified diet 10 = independent	_____
BATHING 0 = dependent 5 = independent (or in shower)	_____
GROOMING 0 = needs to help with personal care 5 = independent face/hair/teeth/shaving (implements provided)	_____
DRESSING 0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	_____
BOWELS 0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	_____
BLADDER 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	_____
TOILET USE 0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	_____
TRANSFERS (BED TO CHAIR AND BACK) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	_____
MOBILITY (ON LEVEL SURFACES) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	_____
STAIRS 0 = unable 5 = needs help (verbal, physical, carrying aid) 10 = independent	_____
TOTAL (0–100):	_____

D6.1 Evaluation framework

A.2.2 Barthel Index of Activities of Daily Living (scores range 0 – 20)

(Ref: Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Int Disabil Stud.* 1988;10(2):61-63)

The Barthel Index

Bowels

- 0 = incontinent (or needs to be given enemata)
- 1 = occasional accident (once/week)
- 2 = continent

Patient's Score: _____

Bladder

- 0 = incontinent, or catheterized and unable to manage
- 1 = occasional accident (max. once per 24 hours)
- 2 = continent (for over 7 days)

Patient's Score: _____

Grooming

- 0 = needs help with personal care
- 1 = independent face/hair/teeth/shaving (implements provided)

Patient's Score: _____

Toilet use

- 0 = dependent
- 1 = needs some help, but can do something alone
- 2 = independent (on and off, dressing, wiping)

Patient's Score: _____

Feeding

- 0 = unable
- 1 = needs help cutting, spreading butter, etc.
- 2 = independent (food provided within reach)

Patient's Score: _____

Transfer

- 0 = unable – no sitting balance
- 1 = major help (one or two people, physical), can sit
- 2 = minor help (verbal or physical)
- 3 = independent

Patient's Score: _____

Mobility

- 0 = immobile
- 1 = wheelchair independent, including corners, etc.
- 2 = walks with help of one person (verbal or physical)
- 3 = independent (but may use any aid, e.g., stick)

Patient's Score: _____

Dressing

- 0 = dependent
- 1 = needs help, but can do about half unaided
- 2 = independent (including buttons, zips, laces, etc.)

Patient's Score: _____

Stairs

- 0 = unable
- 1 = needs help (verbal, physical, carrying aid)
- 2 = independent up and down

Patient's Score: _____

Bathing

- 0 = dependent
- 1 = independent (or in shower)

Patient's Score: _____

Total Score: _____

(Collin et al., 1988)

A.3 Q3. Instrumental Activities of Daily Living Scale (IADL) (mandatory)

A. Ability to use telephone

- | | |
|---|---|
| 1. Operates telephone on own initiative; looks up and dials numbers, etc. | 1 |
| 2. Dials a few well-known numbers | 1 |
| 3. Answers telephone but does not dial | 1 |
| 4. Does not use telephone at all. | 0 |

B. Shopping

- | | |
|---|---|
| 1. Takes care of all shopping needs independently | 1 |
| 2. Shops independently for small purchases | 0 |
| 3. Needs to be accompanied on any shopping trip. | 0 |
| 4. Completely unable to shop. | 0 |

C. Food Preparation

- | | |
|--|---|
| 1. Plans, prepares and serves adequate meals independently | 1 |
| 2. Prepares adequate meals if supplied with ingredients | 0 |
| 3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet. | 0 |
| 4. Needs to have meals prepared and served. | 0 |

D. Housekeeping

- | | |
|--|---|
| 1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help") | 1 |
| 2. Performs light daily tasks such as dishwashing, bed making | 1 |
| 3. Performs light daily tasks but cannot maintain acceptable level of cleanliness. | 1 |
| 4. Needs help with all home maintenance tasks. | 1 |
| 5. Does not participate in any housekeeping tasks. | 0 |

E. Laundry

- | | |
|---|---|
| 1. Does personal laundry completely | 1 |
| 2. Launders small items; rinses stockings, etc. | 1 |
| 3. All laundry must be done by others. | 0 |

F. Mode of Transportation

- | | |
|--|---|
| 1. Travels independently on public transportation or drives own car. | 1 |
| 2. Arranges own travel via taxi, but does not otherwise use public transportation. | 1 |
| 3. Travels on public transportation when accompanied by another. | 0 |
| 4. Travel limited to taxi or automobile with assistance of another. | 0 |
| 5. Does not travel at all | 0 |

G. Responsibility for own medications

- | | |
|--|---|
| 1. Is responsible for taking medication in correct dosages at correct time. | 1 |
| 2. Takes responsibility if medication is prepared in advance in separate dosage. | 0 |
| 3. Is not capable of dispensing own medication. | 0 |

H. Ability to Handle Finances

- | | |
|---|---|
| 1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income. | 1 |
| 2. Manages day-to-day purchases, but needs help with banking, major purchases, etc. | 1 |
| 3. Incapable if handling money. | 0 |

Source: Lawton, M.P., and Brody, E.M. "Assessment of older people: Self-maintaining and instrumental activities of daily living." Gerontologist 9:179-186, (1969).

A.4 Q4: Geriatric Depression Scale (Short Form)

While there are many instruments available to measure depression, the Geriatric Depression Scale (GDS), first created by Yesavage, et al.⁴, has been tested and used extensively with the older population. The GDS Long Form is a brief, 30-item questionnaire in which participants are asked to respond by answering yes or no in reference to how they felt over the past week. A Short Form GDS consisting of 15 questions was developed in 1986 (see below)⁵. Questions from the Long Form GDS which had the highest correlation with depressive symptoms in validation studies were selected for the short version. Of the 15 items, 10 indicated the presence of depression when answered positively, while the rest (question numbers 1, 5, 7, 11, 13) indicated depression when answered negatively. Scores of 0-4 are considered normal, depending on age, education, and complaints; 5-8 indicate mild depression; 9-11 indicate moderate depression; and 12-15 indicate severe depression.

The Short Form is more easily used by physically ill and mildly to moderately demented patients who have short attention spans and/or feel easily fatigued. It takes about 5 - 7 minutes to complete. It has been extensively used in community, acute and long-term care settings. The GDS was found to have a 92% sensitivity and a 89% specificity when evaluated against diagnostic criteria. The validity and reliability of the tool have been supported through both clinical practice and research. In a validation study comparing the Long and Short Forms of the GDS for self-rating of symptoms of depression, both were successful in differentiating depressed from non-depressed adults with a high correlation ($r = .84$, $p < .001$) (Sheikh & Yesavage, 1986).

This scale is in the public domain.

⁴ Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M.B., & Leirer, V.O. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37-49.

⁵ Sheikh, J.I., & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS). Recent evidence and development of a shorter version. In T.L. Brink (Ed.), *Clinical Gerontology: A Guide to Assessment and Intervention* (pp. 165-173). NY: The Haworth Press, Inc.

D6.1 Evaluation framework

Choose the best answer for how you felt over the past week.

No.	Question	Answer	Score
1.	Are you basically satisfied with your life?	YES / No	
2.	Have you dropped many of your activities and interests?	YES / No	
3.	Do you feel that your life is empty?	YES / No	
4.	Do you often get bored?	YES / No	
5.	Are you in good spirits most of the time?	YES / No	
6.	Are you afraid that something bad is going to happen to you?	YES / No	
7.	Do you feel happy most of the time?	YES / No	
8.	Do you often feel helpless?	YES / No	
9.	Do you prefer to stay at home, rather than going out and doing new things?	YES / No	
10.	Do you feel you have more problems with memory than most people?	YES / No	
11.	Do you think it is wonderful to be alive?	YES / No	
12.	Do you feel pretty worthless the way you are now?	YES / No	
13.	Do you feel full of energy?	YES / No	
14.	Do you feel that your situation is hopeless?	YES / No	
15.	Do you think that most people are better off than you are?	YES / No	
TOTAL			

Answers in bold indicate depression. Score 1 point for each bolded answer.

The final score is the tally of the number of depressive answers with the following scores indicating depression.

- 0 – 4 No depression
- 5 – 10 Suggestive of a mild depression
- 11–15 Suggestive of severe depression

A score > 5 points should warrant a follow-up comprehensive assessment.

Source: <http://www.stanford.edu/~yesavage/GDS.html>

A.5 Q5: PIRU questionnaire on user experience of Integrated Care

PIRU questionnaire on user experience of IC. On 8 January 2014, the Picker Institute and Oxford University published their report *Developing measures of people's self-reported experiences of integrated care*, commissioned by the Department of Health in May 2013. It provides 18 questions that were derived from the National Voices integrated care 'I statements' and tested with patients, social care service users and carers.

(Reference: <http://www.pickereurope.org/integrated-care/>).

PIRU is a novel collaboration between the London School of Hygiene & Tropical Medicine (LSHTM), the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE), and the Health and Care Infrastructure Research and Innovation Centre (HaCIRIC) at Imperial College London Business School plus RAND Europe and the Nuffield Trust.

(Reference: <http://www.piru.ac.uk/assets/files/IC%20and%20support%20Pioneers-Indicators.pdf>)

D6.1 Evaluation framework

Question	Carer version	'I' statement	Notes
Q3.1 Have all your needs been assessed? 1 <input type="checkbox"/> All of my needs have been assessed 2 <input type="checkbox"/> Some of my needs have been assessed 3 <input type="checkbox"/> None of my needs have been assessed 4 <input type="checkbox"/> Don't know/can't remember	Q3.1 Have all your needs been assessed? 1 <input type="checkbox"/> All of my needs have been assessed 2 <input type="checkbox"/> Some of my needs have been assessed 3 <input type="checkbox"/> None of my needs have been assessed 4 <input type="checkbox"/> Don't know/can't remember	All my needs as a person are assessed	Q3.1 is being taken forward for further testing for potential inclusion in the Inpatient Survey and ASCS
Q3.2a Were you involved as much as you wanted to be in decisions about your care and support? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	Q3.2a Were you involved as much as you wanted to be in decisions about your care and support? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	I am as involved in discussions and decisions about my care, support and treatment as I want to be	Q3.2a is being taken forward for further testing for potential inclusion in the Inpatient survey and ASCS, but not the Carers Survey (instead Q3.3a (carers version) will be tested)
Q3.2b Were you involved as much as you wanted to be in decisions about your treatment? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	The researchers did not recommend using this question in a survey of carers.	I am as involved in discussions and decisions about my care, support and treatment as I want to be	This question relates to 'treatment', so could be seen as quite health-centric. ICQIDG therefore recommended that survey owners use Q3.2a.
Q3.3a Were your family or carer involved in decisions about your care and support as much as you wanted them to be? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> There were no family or carers available to be involved 5 <input type="checkbox"/> I didn't want my family or carer to be involved in decisions about my care and support	Q3.3a Were you involved as much as you wanted to be in decisions about the care and support of the person you care for? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 3 <input type="checkbox"/> I didn't want to be involved in decisions about care	My family or carer is also involved in these decisions as much as I want them to be	Q3.3a (carers version) has been put forward for further testing for potential inclusion in the Carers Survey
Q3.3b Were your family or carer involved in decisions about your treatment as much as you wanted them to be? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> There were no family or carers available to be involved 5 <input type="checkbox"/> I didn't want my family or carer to be involved in decisions about my treatment and support	Q3.3b Were you involved as much as you wanted to be in decisions about treatment of the person you care for? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 3 <input type="checkbox"/> I didn't want to be involved in decisions about treatment	My family or carer is also involved in these decisions as much as I want them to be	

D6.1 Evaluation framework

Question	Carer version	'I' statement	Notes
Q3.4 Overall, do you feel that your carer/family has had as much support from health and social services as they needed? 1 <input type="checkbox"/> Yes, they have had as much support as they needed 2 <input type="checkbox"/> They have had some support but not as much as they needed 3 <input type="checkbox"/> No, they have had little or no support 4 <input type="checkbox"/> They did not want/need support 5 <input type="checkbox"/> There are no family members or carers to support	Q3.4 Overall, do you feel that you have had as much support from health and social services as you needed? 1 <input type="checkbox"/> Yes, I have had as much support as they needed 2 <input type="checkbox"/> Yes, I have had some support but not as much as I needed 3 <input type="checkbox"/> No, I have had little or no support 4 <input type="checkbox"/> I did not want/need support	My carer/family have their needs recognised and are given support to care for me	Q3.4 is being taken forward for further testing for potential inclusion in the ASCS and the Inpatient Survey
Q3.5 To what extent do you agree or disagree with the following statement: <i>"Health and social care staff always tell me what will happen next"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	Q3.5 To what extent do you agree or disagree with the following statement: <i>"Health and social care staff always tell me what will happen next"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact	This question has been put forward for further testing for potential inclusion in the ASCS, Carers Survey and CMHS.* Responding to concerns raised over the notion of health and social care staff <i>telling</i> people what will happen next, ICQIDG has recommended that a variant should be tested as well or instead of Q3.5: "Q3.5a To what extent do you agree or disagree with the following statement: <i>"Health and social care staff always ensure I know what will happen next"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree" The variant of Q3.5 is being tested for the ASCS, Carers Survey, CMHS and Inpatient Survey.*

D6.1 Evaluation framework

Question	Carer version	'I' statement	Notes
Q3.6 When health or social care staff plan care or treatment for you, does it happen? 1 <input type="checkbox"/> Yes, it happens all of the time 2 <input type="checkbox"/> It happens most of the time 3 <input type="checkbox"/> It happens some of the time 4 <input type="checkbox"/> No	Q3.6 Thinking about the person you care for, when health or social care staff plan care or treatment for them does it happen? 1 <input type="checkbox"/> Yes, it happens all of the time 2 <input type="checkbox"/> It happens most of the time 3 <input type="checkbox"/> It happens some of the time 4 <input type="checkbox"/> No	When something is planned, it happens	This question has been put forward for further testing for potential inclusion in the Carers Survey
Q3.7a To what extent do you agree or disagree with the following statement: <i>"My care and support is reviewed as often as it should be"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	Q3.7a Thinking about the person you care for, to what extent do you agree or disagree with the following statement: <i>"Their care and support is reviewed as often as it should be"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	I have regular reviews of my care and treatment, and of my care and support plan	The carers version of this question has been put forward for further testing for potential inclusion in the Carers Survey
Q3.7b To what extent do you agree or disagree with the following statement: <i>"My treatment is reviewed as often as it should be"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	Q3.7b Thinking about the person you care for, to what extent do you agree or disagree with the following statement: <i>"Their treatment is reviewed as often as it should be"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	I have regular reviews of my care and treatment, and of my care and support plan	
Q3.8 To what extent do you agree or disagree with the following statement: <i>"My medicines are thoroughly reviewed as often as they should be"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	Q3.8 Thinking about the person you care for, to what extent do you agree or disagree with the following statement: <i>"Their medicines are thoroughly reviewed as often as they should be"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	I have regular, comprehensive reviews of my medicines	

D6.1 Evaluation framework

Question	Carer version	'I' statement	Notes
Q3.9 Do you have a named health or social care professional who co-ordinates your care and support? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, I co-ordinate my own care and support 3 <input type="checkbox"/> Don't know/not sure	Q3.9 Do you have a named health or social care professional who co-ordinates your care and support? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, I co-ordinate my own care and support 3 <input type="checkbox"/> Don't know/not sure	I always know who is co-ordinating my care	Q3.9 is being taken forward for the Inpatient Survey and for further testing for potential inclusion in the ASCS, where the following additional answers will be included as Q3.9a: No – I need and/or would like someone to coordinate my care and support No – I don't have multiple needs so my care and support does not need co-ordinating No – For other reasons
Q3.12 If you have questions, when can you contact the people treating and caring for you? Please tick ALL that apply 1 <input type="checkbox"/> During normal working hours 2 <input type="checkbox"/> During the evening 3 <input type="checkbox"/> During the night 4 <input type="checkbox"/> Weekends 5 <input type="checkbox"/> Don't know/not sure	Q3.12 If you have questions, when can you contact the people treating and caring for the person you care for? Please tick ALL that apply 1 <input type="checkbox"/> During normal working hours 2 <input type="checkbox"/> During the evening 3 <input type="checkbox"/> During the night 4 <input type="checkbox"/> Weekends 5 <input type="checkbox"/> Don't know/not sure	I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.	
Q3.13 Do you feel this person understands about you and your condition? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	Q3.13 Do you feel this person understands about the person you care for and their condition? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.	
Q3.14 Do all the different people treating and caring for you work well together to give you the best possible care and support? 1 <input type="checkbox"/> Yes, all of them work well together 2 <input type="checkbox"/> Most of them work well together 3 <input type="checkbox"/> Some of them work well together 4 <input type="checkbox"/> No, they do not work well together 5 <input type="checkbox"/> Don't know/not sure	Q3.14 Thinking about the person you care for, do all the different people treating and caring for them work well together to give the best possible care and support? 1 <input type="checkbox"/> Yes, all of them work well together 2 <input type="checkbox"/> Most of them work well together 3 <input type="checkbox"/> Some of them work well together 4 <input type="checkbox"/> No, they do not work well together 5 <input type="checkbox"/> Don't know/not sure	The professionals involved with my care talk to each other. We all work as a team.	Q3.14 (carers version) has been put forward for further testing for potential inclusion in the CMHS, Inpatient Survey, ASCS and Carers Survey*

D6.1 Evaluation framework

Question	Carer version	'I' statement	Notes
Q3.15 Do health and social care services help you live the life you want as far as possible? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	Q3.15 Do health and social care services help you live the life you want as far as possible? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	Taken together, my care and support help me live the life I want to the best of my ability	Q3.15 is being taken forward for further testing for potential inclusion in the ASCS and Inpatient Survey
Q3.17 To what extent do you agree or disagree with the following statement: <i>"In the last 12 months, health and social care staff have given me information about other services that are available to someone in my circumstances, including support organisations"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	Q3.17 To what extent do you agree or disagree with the following statement: <i>"In the last 12 months, health and social care staff have given me information about other services that are available to someone in my circumstances, including support organisations"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree	I am told about the other services that are available to someone in my circumstances, including support organisations.	This question has been put forward for further testing for potential inclusion in the Carers Survey

A.6 Q6. eCCIS – eCare Client Impact Survey

The eCCIS needs to be adapted to the purposes of a specific evaluation at a given pilot site, depending on the research questions to be answered and other considerations such as overall instrument length / respondent burden or resources available for evaluation. The adaptation consists of the following steps:

1. Decide which module to apply. Delete unused modules.
2. Decide which questions within each module are applicable. Delete questions that are not applicable, add additional questions when needed.
3. Adapt reference to the intervention being measured in each question so that a respondent understands what he/she is being asked about. Possible alternative references are given in square brackets, followed by "xxx AltRef" in each question. Other references can be used. References not used should be deleted.
4. Delete information needed for the setting up of the questionnaire. Paragraphs that can be deleted each begin with "[xxx this paragraph to be deleted]".
5. Delete numeric codes assigned to answer categories [provided in square brackets].

A.6.1 Q6 Version for clients / patients

Module 1: Time use

Explanation for respondent: First, we would like to ask you a few questions about the time you spend using the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>].

Researcher instructions: This module is for measuring the time spent by the respondent for using the service. Depending on the service scenario under investigation, the questions need to be adapted to cover different activities for which time is being spent. Common examples include the time spent doing telehealth readings, time for regular visits by or to a social or health care provider (including travel time, if applicable) or using an online service (such as a patient information website or similar).

D6.1 Evaluation framework

1.	<p>In relation to your usage of the telehealth equipment [xxx AltRef: telemonitoring equipment / <given name of device set> / <given name of service>], can you tell me how often you usually do your telehealth readings?</p> <p> Less than once per week <input type="checkbox"/> [1] </p> <p> About 2 to 4 times a week <input type="checkbox"/> [2] </p> <p> About every day <input type="checkbox"/> [3] </p> <p> More than 1 time per day <input type="checkbox"/> [4] </p> <p> Don't know <input type="checkbox"/> [9] </p>
2.	<p>How much time do you usually spend doing your telehealth [xxx AltRef: telemonitoring / <given name of device set> / <given name of service>] readings?</p> <p> Less than 10 minutes per session <input type="checkbox"/> [1] </p> <p> Between 10 minutes and half an hour per session <input type="checkbox"/> [2] </p> <p> More than half an hour per session <input type="checkbox"/> [3] </p> <p> Don't know <input type="checkbox"/> [9] </p>
3.	<p>In relation to your usage of the telecare equipment [xxx AltRef: social alarm / <given name of device set> / <given name of service>], can you tell me how often you usually use it?</p> <p> Less than once per week <input type="checkbox"/> [1] </p> <p> About 2 to 4 times a week <input type="checkbox"/> [2] </p> <p> About every day <input type="checkbox"/> [3] </p> <p> More than 1 time per day <input type="checkbox"/> [4] </p> <p> Don't know <input type="checkbox"/> [9] </p>
4.	<p>How much time do you usually spend using your telecare [xxx AltRef: social alarm / <given name of device set> / <given name of service>]?</p> <p> Less than 10 minutes per session <input type="checkbox"/> [1] </p> <p> Between 10 minutes and half an hour per session <input type="checkbox"/> [2] </p> <p> More than half an hour per session <input type="checkbox"/> [3] </p> <p> Don't know <input type="checkbox"/> [9] </p>
5.	<p>In relation to your visits to the GP, can you tell me how often you usually go to see him or her?</p> <p> Less than once per month <input type="checkbox"/> [1] </p> <p> 1 to 4 times a month <input type="checkbox"/> [2] </p> <p> More than once per week <input type="checkbox"/> [3] </p> <p> Don't know <input type="checkbox"/> [9] </p>
6.	<p>How much time does one visit usually take you, including the time it takes you to get there?</p> <p> Less than an hour <input type="checkbox"/> [1] </p> <p> Between one and two hours <input type="checkbox"/> [2] </p> <p> More than three hours <input type="checkbox"/> [3] </p> <p> Don't know <input type="checkbox"/> [9] </p>
7.	<p>In relation to your visits to the specialist [xxx AltRef: <type of specialist> (e.g. cardiologist) / <name of individual specialist>], can you tell me how often you usually go to see him or her?</p> <p> Less than once per month <input type="checkbox"/> [1] </p> <p> 1 to 4 times a month <input type="checkbox"/> [2] </p> <p> More than once per week <input type="checkbox"/> [3] </p> <p> Don't know <input type="checkbox"/> [9] </p>
8.	<p>How much time does one visit usually take you, including the time it takes you to get there?</p> <p> Less than an hour <input type="checkbox"/> [1] </p> <p> Between one and two hours <input type="checkbox"/> [2] </p> <p> More than three hours <input type="checkbox"/> [3] </p> <p> Don't know <input type="checkbox"/> [9] </p>
9.	<p>In relation to visits by the home nursing service [xxx AltRef: community nurses / <given name of service> / <name of individual nurse>], can you tell me how often they usually come to see you?</p> <p> Less than once per month <input type="checkbox"/> [1] </p> <p> 1 to 4 times a month <input type="checkbox"/> [2] </p> <p> More than once per week <input type="checkbox"/> [3] </p> <p> Don't know <input type="checkbox"/> [9] </p>

D6.1 Evaluation framework

10.	How much time does one visit usually take?				
	Less than an hour <input type="checkbox"/> [1]	Between one and two hours <input type="checkbox"/> [2]	More than three hours <input type="checkbox"/> [3]	Don't know <input type="checkbox"/> [9]	
11.	In relation to visits by the social care service [xxx AltRef: home care service / <given name of service> / <name of individual nurse>], can you tell me how often they usually come to see you?				
	Less than once per month <input type="checkbox"/> [1]	1 to 4 times a month <input type="checkbox"/> [2]	More than once per week <input type="checkbox"/> [3]	Don't know <input type="checkbox"/> [9]	
12.	How much time does one visit usually take?				
	Less than an hour <input type="checkbox"/> [1]	Between one and two hours <input type="checkbox"/> [2]	More than three hours <input type="checkbox"/> [3]	Don't know <input type="checkbox"/> [9]	
13.	In relation to your usage of the web portal [xxx AltRef: <given name of web portal> / <given name of service>], can you tell me how often you usually access it?				
	Less than once per week <input type="checkbox"/> [1]	About 2 to 4 times a week <input type="checkbox"/> [2]	About every day <input type="checkbox"/> [3]	More than 1 time per day <input type="checkbox"/> [4]	Don't know <input type="checkbox"/> [9]
14.	How much time do you usually spend using the web portal [xxx AltRef: <given name of web portal> / <given name of service>]?				
	Less than 10 minutes per session <input type="checkbox"/> [1]	Between 10 minutes and half an hour per session <input type="checkbox"/> [2]	Between half an hour and 1 hour per session <input type="checkbox"/> [3]	More than 1 hour per session <input type="checkbox"/> [4]	Don't know <input type="checkbox"/> [9]

Module 2: Specific service-related impacts

Explanation for respondent: Now, we would like to ask you a few questions about how you feel the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] has affected you.

Researcher instructions: This module addresses any specific impacts that can be expected to be generated by the service under evaluation and to be perceivable by the respondent. Potential areas of impact to be addressed include the motivation to perform physical activities, the ability to perform physical activities, level of anxiety, sense of safety and security, feeling of independence / self-determination, emotional wellbeing, social connectedness or isolation, ability to manage own chronic disease, or ability to manage activities of daily living.

Where applicable, the term “the new service” should be adapted to the actual name of the service or system, especially if this can be expected to be more familiar to the respondent (e.g. the COPD programme, the telecare service). This may also be necessary if the respondent is actually not aware of anything new being put in place, e.g. because for her/him it is the first contact with the service.

With a view to respondent burden, overlaps with other instruments measuring similar or identical constructs should be avoided. For the same reason, it may also make sense to limit the number of questions used to between three and five.

1.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] affected your motivation to perform daily physical activities?</p> <p><i>It has increased my motivation a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has increased my motivation a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected my motivation</i> <input type="checkbox"/> [3]</p> <p><i>It has decreased my motivation a little</i> <input type="checkbox"/> [4]</p> <p><i>It has decreased my motivation a lot</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>
2.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] affected your ability to perform daily physical activities?</p> <p><i>It has increased my ability a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has increased my ability a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected my ability</i> <input type="checkbox"/> [3]</p> <p><i>It has decreased my ability a little</i> <input type="checkbox"/> [4]</p> <p><i>It has decreased my ability a lot</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>
3	<p>To what extent, if any, has the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] affected your emotional wellbeing?</p> <p><i>It has increased my emotional wellbeing a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has increased my emotional wellbeing a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected my emotional wellbeing</i> <input type="checkbox"/> [3]</p> <p><i>It has decreased my emotional wellbeing a little</i> <input type="checkbox"/> [4]</p> <p><i>It has decreased my emotional wellbeing a lot</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>

D6.1 Evaluation framework

4.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] affected your ability to get along with your health condition in day-to-day life?</p> <p><i>It has increased my ability a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has increased my ability a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected my ability</i> <input type="checkbox"/> [3]</p> <p><i>It has decreased my ability a little</i> <input type="checkbox"/> [4]</p> <p><i>It has decreased my ability a lot</i> <input type="checkbox"/> [5]</p> <hr/> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>
5.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] affected your anxiety about your health condition?</p> <p><i>It has decreased my anxiety about my health a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has decreased my anxiety about my health a little</i> <input type="checkbox"/> [2]</p> <p><i>It has had no impact on my anxiety about my health</i> <input type="checkbox"/> [3]</p> <p><i>It has increased my anxiety about my health a little</i> <input type="checkbox"/> [4]</p> <p><i>It has increased my anxiety about my health a lot</i> <input type="checkbox"/> [5]</p> <hr/> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>
6.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] affected how lonely you feel?</p> <p><i>It has decreased how lonely I feel a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has decreased how lonely I feel a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected how lonely I feel</i> <input type="checkbox"/> [3]</p> <p><i>It has increased how lonely I feel a little</i> <input type="checkbox"/> [4]</p> <p><i>It has increased how lonely I feel a lot</i> <input type="checkbox"/> [5]</p> <hr/> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>

D6.1 Evaluation framework

7.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] affected your relationship with your family carer?</p> <p><i>It has improved our relationship a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has improved our relationship a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected our relationship</i> <input type="checkbox"/> [3]</p> <p><i>It has made our relationship a little worse</i> <input type="checkbox"/> [4]</p> <p><i>It has made our relationship a lot worse</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>
8.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] affected your relationship with the professional carers looking after you?</p> <p><i>It has improved our relationship a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has improved our relationship a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected our relationship</i> <input type="checkbox"/> [3]</p> <p><i>It has made our relationship a little worse</i> <input type="checkbox"/> [4]</p> <p><i>It has made our relationship a lot worse</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>

Module 3: Summary assessment

Explanation for respondent: Now, we would like to ask you a few questions about how satisfied you are in general with the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>].

Researcher instructions: Module 3 covers the overall satisfaction of the respondent with the service received. Its main aim is to determine in how far specific benefits or dis-benefits were perceived as being crucial for the overall experience. Furthermore it addresses the issue of service sustainability from the respondent's point of view.

1.	<p>Overall, taking everything into account, how satisfied are you with the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>]?</p>				
	<p><i>Very satisfied</i></p> <p><input type="checkbox"/> [1]</p>	<p><i>Fairly satisfied</i></p> <p><input type="checkbox"/> [2]</p>	<p><i>Neither satisfied nor dissatisfied</i></p> <p><input type="checkbox"/> [3]</p>	<p><i>Fairly dissatisfied</i></p> <p><input type="checkbox"/> [4]</p>	<p><i>Very dissatisfied</i></p> <p><input type="checkbox"/> [5]</p>

	<p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>										
2.	<p>Again, taking everything into account, is the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] worth the effort involved in using it?</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: center; width: 20%;">Yes <i>Very much so</i></td> <td style="text-align: center; width: 20%;">Yes <i>mostly</i></td> <td style="text-align: center; width: 20%;">Neither worth it <i>nor not worth it</i></td> <td style="text-align: center; width: 20%;">No <i>mostly not</i></td> <td style="text-align: center; width: 20%;">No <i>certainly not</i></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/> [1]</td> <td style="text-align: center;"><input type="checkbox"/> [2]</td> <td style="text-align: center;"><input type="checkbox"/> [3]</td> <td style="text-align: center;"><input type="checkbox"/> [4]</td> <td style="text-align: center;"><input type="checkbox"/> [5]</td> </tr> </table> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>	Yes <i>Very much so</i>	Yes <i>mostly</i>	Neither worth it <i>nor not worth it</i>	No <i>mostly not</i>	No <i>certainly not</i>	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]
Yes <i>Very much so</i>	Yes <i>mostly</i>	Neither worth it <i>nor not worth it</i>	No <i>mostly not</i>	No <i>certainly not</i>							
<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]							
3.	<p>Would you want to continue using the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] in the future?</p> <p>[xxx AltQst] Would you want to use the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] again, in case you should need it?</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: center; width: 20%;">Definitely <i>yes</i></td> <td style="text-align: center; width: 20%;">Probably <i>yes</i></td> <td style="text-align: center; width: 20%;">I am not yet <i>decided</i></td> <td style="text-align: center; width: 20%;">Probably <i>not</i></td> <td style="text-align: center; width: 20%;">Certainly <i>not</i></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/> [1]</td> <td style="text-align: center;"><input type="checkbox"/> [2]</td> <td style="text-align: center;"><input type="checkbox"/> [3]</td> <td style="text-align: center;"><input type="checkbox"/> [4]</td> <td style="text-align: center;"><input type="checkbox"/> [5]</td> </tr> </table> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>	Definitely <i>yes</i>	Probably <i>yes</i>	I am not yet <i>decided</i>	Probably <i>not</i>	Certainly <i>not</i>	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]
Definitely <i>yes</i>	Probably <i>yes</i>	I am not yet <i>decided</i>	Probably <i>not</i>	Certainly <i>not</i>							
<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]							

Module 4: willingness-to-pay

Researcher instructions: Module 4 measures the respondent's willingness to pay for the new service. The module should be primarily used in cases where the introduction of a service fee is being considered, in order to determine what amounts might be acceptable to what parts of the target population.

The module comes in two versions, one for self-completion and a second for application by an interviewer.

Note that the introductory text is integral part of the module and should be applied. It needs to be adapted to the specific evaluation. Since willingness to pay is usually strongly dependent on income, the respective questions should be applied as long as there is no case-level data on income from the same respondents.

Currency amounts, both for the possible fee and for household income categories, need to be adapted to the circumstances of the area where the service is being evaluated.

WTP for self-completion

Introduction (please adapt)

We would like to find out how valuable the service that you have received in the past months is to you, especially with respect to your <health/wellbeing/other>. We have therefore designed a short questionnaire for you to complete.

D6.1 Evaluation framework

We are asking you to imagine a situation where you have to pay a monthly fee for the service. The amount of the fee you would be willing to pay (if you had to) gives us an indication of how you value <health/wellbeing/other> gains from the service compared with other things you might want to spend your money on. There are no right or wrong answers.

Please read each question carefully and follow the instructions. This questionnaire is confidential and no identifying information will be used.

1.	Thinking just about your health and wellbeing, would the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] be worth at least something to you?						
	Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] → Please tell us why below (Question 3).						
2.	<p>Now suppose that you were told that the monthly fee for the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] would be one of the amounts given below. Would you say 'Yes, I'd pay that' or 'No, I'd rather live without the service's help'? Or would you be unsure?</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 33%; text-align: center; vertical-align: top;"> <div style="text-align: right; font-weight: bold; margin-bottom: 5px;">10€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div> </td> <td style="width: 33%; text-align: center; vertical-align: top;"> <div style="text-align: right; font-weight: bold; margin-bottom: 5px;">20€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div> </td> <td style="width: 33%; text-align: center; vertical-align: top;"> <div style="text-align: right; font-weight: bold; margin-bottom: 5px;">30€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div> </td> </tr> </table>	<div style="text-align: right; font-weight: bold; margin-bottom: 5px;">10€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div>	<div style="text-align: right; font-weight: bold; margin-bottom: 5px;">20€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div>	<div style="text-align: right; font-weight: bold; margin-bottom: 5px;">30€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div>			
<div style="text-align: right; font-weight: bold; margin-bottom: 5px;">10€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div>	<div style="text-align: right; font-weight: bold; margin-bottom: 5px;">20€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div>	<div style="text-align: right; font-weight: bold; margin-bottom: 5px;">30€ per month</div> <div style="display: flex; justify-content: space-between;"> Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] Unsure <input type="checkbox"/> [3] </div>					
3.	<p>If the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] is not worth anything to you, please let us know why you feel this way:</p> <hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/> <hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/> <hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>						
4.	<p>To be able to better understand your answer, could you please tell us what the monthly net income of your household is? (Net income is the income of all household members, regardless of source, less taxation and compulsory insurance).</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 16.6%; text-align: center; vertical-align: top;">Less than 1200 € <input type="checkbox"/> [1]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">Between 1200 and 2000 € <input type="checkbox"/> [2]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">Between 2000 and 4000 € <input type="checkbox"/> [3]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">More than 4000 € <input type="checkbox"/> [4]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">I don't know → go to question 5 <input type="checkbox"/> [8]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">I would rather not tell → go to question 5 <input type="checkbox"/> [9]</td> </tr> </table>	Less than 1200 € <input type="checkbox"/> [1]	Between 1200 and 2000 € <input type="checkbox"/> [2]	Between 2000 and 4000 € <input type="checkbox"/> [3]	More than 4000 € <input type="checkbox"/> [4]	I don't know → go to question 5 <input type="checkbox"/> [8]	I would rather not tell → go to question 5 <input type="checkbox"/> [9]
Less than 1200 € <input type="checkbox"/> [1]	Between 1200 and 2000 € <input type="checkbox"/> [2]	Between 2000 and 4000 € <input type="checkbox"/> [3]	More than 4000 € <input type="checkbox"/> [4]	I don't know → go to question 5 <input type="checkbox"/> [8]	I would rather not tell → go to question 5 <input type="checkbox"/> [9]		
5.	<p>If you do not know the exact amount or do not want to reply to this question, could you tell us which of the following statements best describes your current financial situation?</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 16.6%; text-align: center; vertical-align: top;">Things are very difficult <input type="checkbox"/> [1]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">I have trouble making ends meet <input type="checkbox"/> [2]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">I have to be careful but I get by <input type="checkbox"/> [3]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">Comfortable <input type="checkbox"/> [4]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">Very comfortable <input type="checkbox"/> [5]</td> <td style="width: 16.6%; text-align: center; vertical-align: top;">Don't know or would rather not tell <input type="checkbox"/> [9]</td> </tr> </table>	Things are very difficult <input type="checkbox"/> [1]	I have trouble making ends meet <input type="checkbox"/> [2]	I have to be careful but I get by <input type="checkbox"/> [3]	Comfortable <input type="checkbox"/> [4]	Very comfortable <input type="checkbox"/> [5]	Don't know or would rather not tell <input type="checkbox"/> [9]
Things are very difficult <input type="checkbox"/> [1]	I have trouble making ends meet <input type="checkbox"/> [2]	I have to be careful but I get by <input type="checkbox"/> [3]	Comfortable <input type="checkbox"/> [4]	Very comfortable <input type="checkbox"/> [5]	Don't know or would rather not tell <input type="checkbox"/> [9]		
6.	<p>Is there anything else you would like to add about how valuable the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] is to you?</p> <hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/> <hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/> <hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>						

D6.1 Evaluation framework

Note to interviewer

In applying this questionnaire, please follow the instructions given throughout the document. These are always marked with the abbreviation INT followed by a colon and the instruction. Start by reading the introduction text to the respondent, then go to question 1, reading out the question and the answer options. Depending on the answers given, continue with the next question as indicated. If there is no question indicated, please continue with the one immediately following.

INT: Read aloud to respondent. (please adapt)

We would like to find out how valuable the service that you have received in the past months is to you, especially with respect to your <health/wellbeing/other>. We have therefore designed a short questionnaire for you to complete.

We are asking you to imagine a situation where you have to pay a monthly fee for the service. The amount of the fee you would be willing to pay (if you had to) gives us an indication of how you value <health/wellbeing/other> gains from the service compared with other things you might want to spend your money on. There are no right or wrong answers.

This questionnaire is confidential and no identifying information will be used.

1.	Thinking just about your health and wellbeing, would the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] be worth at least something to you? Yes <input type="checkbox"/> [1] → INT: go to question 3 No <input type="checkbox"/> [2] → INT: go to question 2
2.	Please explain why the service is not worth anything to you? _____ _____ _____ → INT: Got to question 7
3.	Suppose that you were told that the fee for new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] would be 20€ per month. Would you say 'Yes, I'll pay that' or 'No, I'd rather live without the service's help'? Or would you be unsure? Yes <input type="checkbox"/> [1] → INT: go to question 5 Unsure <input type="checkbox"/> [2] → INT: go to question 5 No <input type="checkbox"/> [3] → INT: go to question 4
4.	Is there any amount less than 20€ that you would be prepared to pay per month? Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] If yes, what is the most you would be prepared to pay? _____ _____ → INT: Got to question 7
5.	Suppose that you were told instead that the fee for the new service [xxx AltRef: the service / the care you received in relation to your condition / <given name of service>] would be 30€ per month. Would you say 'Yes, I'll pay that' or 'No, I'd rather live without the service's help'? Or would you be unsure? Yes <input type="checkbox"/> [1] → INT: go to question 6 Unsure <input type="checkbox"/> [2] → INT: go to question 6 No <input type="checkbox"/> [3] → INT: go to question 6
6.	What is the HIGHEST fee you would be prepared to pay per month for the new service [xxx AltRef: the

D6.1 Evaluation framework

	service / the care you received in relation to your condition / <given name of service>]?					
	→ INT: Got to question 7					
7.	To be able to better understand your answer given in the last question, could you please tell us what the monthly net income of your household is? (Net income is the income of all household members, regardless of source, less taxation and compulsory insurance).					
	Less than 1200 €	Between 1200 and 2000 €	Between 2000 and 4000 €	More than 4000 €	I don't know → INT: go to question 8	I would rather not tell → INT: go to question 8
	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [8]	<input type="checkbox"/> [9]
8.	If you do not know the exact amount, or do not want to reply to this question, could you tell us which of the following statements best describes your current financial situation?					
	Things are very difficult	I have trouble making ends meet	I have to be careful but I get by	Comfortable	Very comfortable	Don't know or would rather not tell
	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]	<input type="checkbox"/> [9]

A.6.2 Q6 Version for informal carers

Module 1: Time use

Explanation for respondent: First, we would like to ask you a few questions about the time you spend using the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>].

Researcher instructions: This module is for measuring the time spent by the respondent in using the service. Depending on the service scenario under investigation, the questions need to be adapted to cover different activities for which time is being spent. Common examples include the time spent helping a cared-for person doing telehealth readings, time for accompanying the cared for person on visits to health and care providers, time for own visits by or to a carer support service or time for using an online service (such as an information website).

1.	In relation to the telehealth equipment [xxx AltRef: telemonitoring equipment / <given name of device set> / <given name of service>] used by the person you are caring for, can you tell me how often you usually help the person doing the telehealth readings?				
	Less than once per week	About 1 to 4 times a week	About every day	More than 1 time per day	Don't know
	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [9]
2.	How much time do you usually spend helping with the telehealth [xxx AltRef: telemonitoring / <given name of device set> / <given name of service>] readings?				
	A very short time, say less than 10 minutes per session	A longer time, say between 10 minutes and half an hour per session	A long time, say more than half an hour per session	Don't know	
	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [9]	
3.	In relation to the telecare equipment [xxx AltRef: social alarm / <given name of device set> / <given name of service>] used by the person you are caring for, can you tell me how often you usually help the person using it?				

D6.1 Evaluation framework

	Less than once per week <input type="checkbox"/> [1]	About 1 to 4 times a week <input type="checkbox"/> [2]	About every day <input type="checkbox"/> [3]	More than 1 time per day <input type="checkbox"/> [4]	Don't know <input type="checkbox"/> [9]
4.	<p>How much time do you usually spend helping with the telecare [xxx AltRef: social alarm / <given name of device set> / <given name of service>]?</p> <p>A very short time, say less than 10 minutes per session <input type="checkbox"/> [1]</p> <p>A longer time, say between 10 minutes and half an hour per session <input type="checkbox"/> [2]</p> <p>A long time, say more than half an hour per session <input type="checkbox"/> [3]</p> <p>Don't know <input type="checkbox"/> [9]</p>				
5.	<p>In relation to visits to the GP by the person you are caring for, can you tell me how often you usually go with the person to see him or her?</p> <p>Less than once per month <input type="checkbox"/> [1]</p> <p>1 to 4 times a month <input type="checkbox"/> [2]</p> <p>More than once per week <input type="checkbox"/> [3]</p> <p>Don't know <input type="checkbox"/> [9]</p>				
6.	<p>How much time does going on one visit usually take you, including the time it takes you to get there?</p> <p>A short time, say less than an hour <input type="checkbox"/> [1]</p> <p>A longer time, say between one and two hours <input type="checkbox"/> [2]</p> <p>A long time, say more than three hours <input type="checkbox"/> [3]</p> <p>Don't know <input type="checkbox"/> [9]</p>				
7.	<p>In relation to visits to the specialist [xxx AltRef: <type of specialist> (e.g. cardiologist) / <name of individual specialist>] by the person you are caring for, can you tell me how often you usually go with the person to see him or her?</p> <p>Less than once per month <input type="checkbox"/> [1]</p> <p>1 to 4 times a month <input type="checkbox"/> [2]</p> <p>More than once per week <input type="checkbox"/> [3]</p> <p>Don't know <input type="checkbox"/> [9]</p>				
8.	<p>How much time does going on one visit usually take you, including the time it takes you to get there?</p> <p>A short time, say less than an hour <input type="checkbox"/> [1]</p> <p>A longer time, say between one and two hours <input type="checkbox"/> [2]</p> <p>A long time, say more than three hours <input type="checkbox"/> [3]</p> <p>Don't know <input type="checkbox"/> [9]</p>				
9.	<p>In relation to your own participation in care planning meetings [xxx AltRef: care planning meetings held by <provider> / <given name of meetings>], can you tell me how often you usually go there?</p> <p>Less than once every half year <input type="checkbox"/> [1]</p> <p>Every 4 to 6 months <input type="checkbox"/> [2]</p> <p>Every 1 to 3 months <input type="checkbox"/> [3]</p> <p>More than once per month <input type="checkbox"/> [4]</p> <p>Don't know <input type="checkbox"/> [9]</p>				
10.	<p>How much time does going on one meeting usually take you, including the time it takes you to get there?</p> <p>A short time, say less than an hour <input type="checkbox"/> [1]</p> <p>A longer time, say between one and two hours <input type="checkbox"/> [2]</p> <p>A long time, say more than three hours <input type="checkbox"/> [3]</p> <p>Don't know <input type="checkbox"/> [9]</p>				
11.	<p>In relation to your own visits to the carer support organization [xxx AltRef: <given name of organization>], can you tell me how often you usually go there?</p> <p>Less than once per month <input type="checkbox"/> [1]</p> <p>1 to 4 times a month <input type="checkbox"/> [2]</p> <p>More than once per week <input type="checkbox"/> [3]</p> <p>Don't know <input type="checkbox"/> [9]</p>				

D6.1 Evaluation framework

	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [9]
12.	How much time does going on one visit usually take you, including the time it takes you to get there?			
	A short time, say less than an hour <input type="checkbox"/> [1]	A longer time, say between one and two hours <input type="checkbox"/> [2]	A long time, say more than three hours <input type="checkbox"/> [3]	Don't know <input type="checkbox"/> [9]
13.	In relation to your usage of the web portal [xxx AltRef: <given name of web portal> / <given name of service>], can you tell me how often you usually access it?			
	Less than once per week <input type="checkbox"/> [1]	About 1 to 4 times a week <input type="checkbox"/> [2]	About every day <input type="checkbox"/> [3]	More than 1 time per day <input type="checkbox"/> [4] Don't know <input type="checkbox"/> [9]
14.	How much time do you usually spend using the web portal [xxx AltRef: <given name of web portal> / <given name of service>]?			
	A very short time, say less than 10 minutes per session <input type="checkbox"/> [1]	A shorter time, say between 10 minutes and half an hour per session <input type="checkbox"/> [2]	A longer time, say between half an hour and 1 hour per session <input type="checkbox"/> [3]	A long time, say more than 1 hour per session <input type="checkbox"/> [4] Don't know <input type="checkbox"/> [9]

Module 2: Specific service-related impacts

Explanation for respondent: Now, we would like to ask you a few questions about how you feel the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] has affected you.

Researcher instructions: This module addresses any specific impacts that can be expected to be generated by the service under evaluation and to be perceivable by the respondent. Potential areas of impact to be addressed include the motivation to perform physical activities, the ability to perform physical activities, level of anxiety, sense of safety and security, feeling of independence / self-determination, emotional wellbeing, social connectedness or isolation, ability to manage own chronic disease, or ability to manage activities of daily living.

Where applicable, the term “the new service” should be adapted to the actual name of the service or system, especially if this can be expected to be more familiar to the respondent (e.g. the COPD programme, the telecare service). This may also be necessary if the respondent is actually not aware of anything new being put in place, e.g. because for her/him it is the first contact with the service.

With a view to respondent burden, overlaps with other instruments measuring similar or identical constructs should be avoided. For the same reason, it may also make sense to limit the number of questions used to between three and five.

1.	To what extent, if any, has the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] affected your ability to manage the care activities you are doing for the person you are caring for?
	<i>It has increased my ability a lot</i> <input type="checkbox"/> [1] <i>It has increased my ability a little</i> <input type="checkbox"/> [2] <i>It has not changed my ability</i> <input type="checkbox"/> [3] <i>It has decreased my ability a little</i> <input type="checkbox"/> [4] <i>It has decreased my ability a lot</i> <input type="checkbox"/> [5]
	<u>If you want to, you can provide further details on your answer below :</u>

	<hr/> <hr/> <hr/>
2.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] affected your relationship with the person you care for?</p> <p><i>It has improved our relationship a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has improved our relationship a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected our relationship</i> <input type="checkbox"/> [3]</p> <p><i>It has made our relationship a little worse</i> <input type="checkbox"/> [4]</p> <p><i>It has made our relationship a lot worse</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>
3.	<p>To what extent, if any, do you feel that the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] supports you in your role as a carer?</p> <p><i>It makes me feel a lot more supported</i> <input type="checkbox"/> [1]</p> <p><i>It makes me feel a little more supported</i> <input type="checkbox"/> [2]</p> <p><i>It has not changed how supported I feel</i> <input type="checkbox"/> [3]</p> <p><i>It makes me feel a little less supported</i> <input type="checkbox"/> [4]</p> <p><i>It makes me feel a lot less supported</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>
4.	<p>To what extent, if any, has using the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] affected your level of anxiety about the health and wellbeing of the person you care for?</p> <p><i>It has reduced my anxiety a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has reduced my anxiety a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected my anxiety</i> <input type="checkbox"/> [3]</p> <p><i>It has increased my anxiety a little</i> <input type="checkbox"/> [4]</p> <p><i>It has increased my anxiety a lot</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>

D6.1 Evaluation framework

5.	<p>To what extent, if any, has the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] affected your emotional wellbeing?</p> <p><i>It has increased my emotional wellbeing a lot</i> <input type="checkbox"/> [1]</p> <p><i>It has increased my emotional wellbeing a little</i> <input type="checkbox"/> [2]</p> <p><i>It has not affected my emotional wellbeing</i> <input type="checkbox"/> [3]</p> <p><i>It has decreased my emotional wellbeing a little</i> <input type="checkbox"/> [4]</p> <p><i>It has decreased my emotional wellbeing a lot</i> <input type="checkbox"/> [5]</p> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>
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Module 3: Summary assessment

Explanation for respondent: Now, we would like to ask you a few questions about how satisfied you are in general with the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>].

Researcher instructions: Module 3 covers the overall satisfaction of the respondent with the service received. Its main aim is to determine in how far specific benefits or dis-benefits were perceived as being crucial for the overall experience. Furthermore it addresses the issue of service sustainability from the respondent's point of view.

1.	<p>Overall, taking everything into account, how satisfied are you with the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>]?</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="text-align: center; width: 20%;"><i>Very satisfied</i></td> <td style="text-align: center; width: 20%;"><i>Fairly satisfied</i></td> <td style="text-align: center; width: 20%;"><i>Neither satisfied nor dissatisfied</i></td> <td style="text-align: center; width: 20%;"><i>Fairly dissatisfied</i></td> <td style="text-align: center; width: 20%;"><i>Very dissatisfied</i></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/> [1]</td> <td style="text-align: center;"><input type="checkbox"/> [2]</td> <td style="text-align: center;"><input type="checkbox"/> [3]</td> <td style="text-align: center;"><input type="checkbox"/> [4]</td> <td style="text-align: center;"><input type="checkbox"/> [5]</td> </tr> </table> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>	<i>Very satisfied</i>	<i>Fairly satisfied</i>	<i>Neither satisfied nor dissatisfied</i>	<i>Fairly dissatisfied</i>	<i>Very dissatisfied</i>	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]
<i>Very satisfied</i>	<i>Fairly satisfied</i>	<i>Neither satisfied nor dissatisfied</i>	<i>Fairly dissatisfied</i>	<i>Very dissatisfied</i>							
<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]							
2.	<p>Again, taking everything into account, is the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] worth the effort involved in using it?</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="text-align: center; width: 20%;"><i>Yes Very much so</i></td> <td style="text-align: center; width: 20%;"><i>Yes mostly</i></td> <td style="text-align: center; width: 20%;"><i>Neither worth it nor not worth it</i></td> <td style="text-align: center; width: 20%;"><i>No mostly not</i></td> <td style="text-align: center; width: 20%;"><i>No certainly not</i></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/> [1]</td> <td style="text-align: center;"><input type="checkbox"/> [2]</td> <td style="text-align: center;"><input type="checkbox"/> [3]</td> <td style="text-align: center;"><input type="checkbox"/> [4]</td> <td style="text-align: center;"><input type="checkbox"/> [5]</td> </tr> </table> <p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>	<i>Yes Very much so</i>	<i>Yes mostly</i>	<i>Neither worth it nor not worth it</i>	<i>No mostly not</i>	<i>No certainly not</i>	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]
<i>Yes Very much so</i>	<i>Yes mostly</i>	<i>Neither worth it nor not worth it</i>	<i>No mostly not</i>	<i>No certainly not</i>							
<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]							

D6.1 Evaluation framework

3.	<p>Would you want to continue using the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] in the future?</p> <p>[xxx AltQst] Would you want to use the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] again, in case it should be necessary?</p>										
	<table style="width: 100%; border: none;"> <tr> <td style="text-align: center; width: 20%;">Yes, <i>very much so</i></td> <td style="text-align: center; width: 20%;">Yes <i>I think so</i></td> <td style="text-align: center; width: 20%;">I am not yet <i>decided</i></td> <td style="text-align: center; width: 20%;">No <i>I do not think so</i></td> <td style="text-align: center; width: 20%;">No <i>certainly not</i></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/> [1]</td> <td style="text-align: center;"><input type="checkbox"/> [2]</td> <td style="text-align: center;"><input type="checkbox"/> [3]</td> <td style="text-align: center;"><input type="checkbox"/> [4]</td> <td style="text-align: center;"><input type="checkbox"/> [5]</td> </tr> </table>	Yes, <i>very much so</i>	Yes <i>I think so</i>	I am not yet <i>decided</i>	No <i>I do not think so</i>	No <i>certainly not</i>	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]
Yes, <i>very much so</i>	Yes <i>I think so</i>	I am not yet <i>decided</i>	No <i>I do not think so</i>	No <i>certainly not</i>							
<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]							
	<p><u>If you want to, you can provide further details on your answer below :</u></p> <hr/> <hr/> <hr/>										

Module 4: Willingness-to-pay

Researcher instructions: Module 4 measures the respondent's willingness to pay for the new service. The module should be primarily used in cases where the introduction of a service fee is being considered, in order to determine what amounts might be acceptable to what parts of the target population.

The module comes in two versions, one for self-completion and a second for application by an interviewer.

Note that the introductory text is integral part of the module and must be applied. It needs to be adapted to the specific evaluation. Since willingness to pay is usually strongly dependent on income, the respective questions should be applied as long as there is no case-level data on income from the same respondents.

Currency amounts, both for the possible fee and for household income categories, need to be adapted to the circumstances of the area where the service is being evaluated.

WTP for self-completion

Introduction (please adapt)

We would like to find out how valuable the service that you have received in the past months is to you, especially with respect to your <role as a carer / the support you receive as a carer>. We have therefore designed a short questionnaire for you to complete.

We are asking you to imagine a situation where you have to pay a monthly fee for the service. The amount of the fee you would be willing to pay (if you had to) gives us an indication of how you value the benefits of the service compared with other things you might want to spend your money on. There are no right or wrong answers.

Please read each question carefully and follow the instructions. This questionnaire is confidential and no identifying information will be used.

1.	<p>Thinking just about your role as a carer, would the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] be worth at least something to you?</p> <p>Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2] → Please tell us why below (Question 3).</p>
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D6.1 Evaluation framework

2.	<p>Now suppose that you were told that the monthly fee for the service would be one of the amounts given below. Would you say 'Yes, I'd pay that' or 'No, I'd rather live without the service's help'? Or would you be unsure?</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <th style="width: 33%; text-align: center;">10€ per month</th> <th style="width: 33%; text-align: center;">20€ per month</th> <th style="width: 33%; text-align: center;">30€ per month</th> </tr> <tr> <td>Yes <input type="checkbox"/> [1]</td> <td>Yes <input type="checkbox"/> [1]</td> <td>Yes <input type="checkbox"/> [1]</td> </tr> <tr> <td>No <input type="checkbox"/> [2]</td> <td>No <input type="checkbox"/> [2]</td> <td>No <input type="checkbox"/> [2]</td> </tr> <tr> <td>Unsure <input type="checkbox"/> [3]</td> <td>Unsure <input type="checkbox"/> [3]</td> <td>Unsure <input type="checkbox"/> [3]</td> </tr> </table>	10€ per month	20€ per month	30€ per month	Yes <input type="checkbox"/> [1]	Yes <input type="checkbox"/> [1]	Yes <input type="checkbox"/> [1]	No <input type="checkbox"/> [2]	No <input type="checkbox"/> [2]	No <input type="checkbox"/> [2]	Unsure <input type="checkbox"/> [3]	Unsure <input type="checkbox"/> [3]	Unsure <input type="checkbox"/> [3]
10€ per month	20€ per month	30€ per month											
Yes <input type="checkbox"/> [1]	Yes <input type="checkbox"/> [1]	Yes <input type="checkbox"/> [1]											
No <input type="checkbox"/> [2]	No <input type="checkbox"/> [2]	No <input type="checkbox"/> [2]											
Unsure <input type="checkbox"/> [3]	Unsure <input type="checkbox"/> [3]	Unsure <input type="checkbox"/> [3]											
3.	<p>If the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] is not worth anything to you, please let us know why you feel this way:</p> <hr/> <hr/> <hr/>												
4.	<p>To be able to better understand your answer, could you please tell us what the monthly net income of your household is? (Net income is the income of all household members, regardless of source, less taxation and compulsory insurance).</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <th style="width: 16.6%;">Less than 1200 €</th> <th style="width: 16.6%;">Between 1200 and 2000 €</th> <th style="width: 16.6%;">Between 2000 and 4000 €</th> <th style="width: 16.6%;">More than 4000 €</th> <th style="width: 16.6%;">I don't know → go to question 5</th> <th style="width: 16.6%;">I would rather not tell → go to question 5</th> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/> [1]</td> <td style="text-align: center;"><input type="checkbox"/> [2]</td> <td style="text-align: center;"><input type="checkbox"/> [3]</td> <td style="text-align: center;"><input type="checkbox"/> [4]</td> <td style="text-align: center;"><input type="checkbox"/> [8]</td> <td style="text-align: center;"><input type="checkbox"/> [9]</td> </tr> </table>	Less than 1200 €	Between 1200 and 2000 €	Between 2000 and 4000 €	More than 4000 €	I don't know → go to question 5	I would rather not tell → go to question 5	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [8]	<input type="checkbox"/> [9]
Less than 1200 €	Between 1200 and 2000 €	Between 2000 and 4000 €	More than 4000 €	I don't know → go to question 5	I would rather not tell → go to question 5								
<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [8]	<input type="checkbox"/> [9]								
5.	<p>If you do not know the exact amount or do not want to reply to this question, could you tell us which of the following statements best describes your current financial situation?</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <th style="width: 16.6%;">Things are very difficult</th> <th style="width: 16.6%;">I have trouble making ends meet</th> <th style="width: 16.6%;">I have to be careful but I get by</th> <th style="width: 16.6%;">Comfortable</th> <th style="width: 16.6%;">Very comfortable</th> <th style="width: 16.6%;">Don't know or would rather not tell</th> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/> [1]</td> <td style="text-align: center;"><input type="checkbox"/> [2]</td> <td style="text-align: center;"><input type="checkbox"/> [3]</td> <td style="text-align: center;"><input type="checkbox"/> [4]</td> <td style="text-align: center;"><input type="checkbox"/> [5]</td> <td style="text-align: center;"><input type="checkbox"/> [9]</td> </tr> </table>	Things are very difficult	I have trouble making ends meet	I have to be careful but I get by	Comfortable	Very comfortable	Don't know or would rather not tell	<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]	<input type="checkbox"/> [9]
Things are very difficult	I have trouble making ends meet	I have to be careful but I get by	Comfortable	Very comfortable	Don't know or would rather not tell								
<input type="checkbox"/> [1]	<input type="checkbox"/> [2]	<input type="checkbox"/> [3]	<input type="checkbox"/> [4]	<input type="checkbox"/> [5]	<input type="checkbox"/> [9]								
6.	<p>Is there anything else you would like to add about how valuable the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] is to you?</p> <hr/> <hr/> <hr/>												

WTP for interview application

Note to interviewer

In applying this questionnaire, please follow the instructions given throughout the document. These are always marked with the abbreviation INT followed by a colon and the instruction. Start by reading the introduction text to the respondent, then go to question 1, reading out the question and the answer options. Depending on the answers given, continue with the next question as indicated. If there is no question indicated, please continue with the one immediately following.

INT: Read aloud to respondent. (please adapt)

We would like to find out how valuable the service that you have received in the past months is to you, especially with respect to your <role as a carer / the support your receive as a carer>. We have therefore designed a short questionnaire for you to complete.

D6.1 Evaluation framework

We are asking you to imagine a situation where you have to pay a monthly fee for the service. The amount of the fee you would be willing to pay (if you had to) gives us an indication of how you value the benefits of the service compared with other things you might want to spend your money on. There are no right or wrong answers.

This questionnaire is confidential and no identifying information will be used.

1.	<p>Thinking just about your role as a carer, would the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] be worth at least something to you?</p> <p>Yes <input type="checkbox"/> [1] → INT: go to question 3 No <input type="checkbox"/> [2] → INT: go to question 2</p>
2.	<p>Please explain why the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] is not worth anything to you?</p> <hr/> <hr/> <hr/> <p>→ INT: Got to question 7</p>
3.	<p>Suppose that you were told that the fee for the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] would be 20€ per month. Would you say 'Yes, I'd pay that' or 'No, I'd rather live without the service's help'? Or would you be unsure?</p> <p>Yes <input type="checkbox"/> [1] → INT: go to question 5 Unsure <input type="checkbox"/> [2] → INT: go to question 5 No <input type="checkbox"/> [3] → INT: go to question 4</p>
4.	<p>Is there any amount less than 20€ that you would be prepared to pay per month?</p> <p>Yes <input type="checkbox"/> [1] No <input type="checkbox"/> [2]</p> <p>If yes, what is the most you would be prepared to pay?</p> <hr/> <hr/> <p>→ INT: Got to question 7</p>
5.	<p>Suppose that you were told instead that the fee for the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>] would be 30€ per month. Would you say 'Yes, I'll pay that' or 'No, I'd rather live without the service's help'? Or would you be unsure?</p> <p>Yes <input type="checkbox"/> [1] → INT: go to question 6 Unsure <input type="checkbox"/> [2] → INT: go to question 6 No <input type="checkbox"/> [3] → INT: go to question 6</p>
6.	<p>What is the HIGHEST fee you would be prepared to pay per month for the new service [xxx AltRef: the service / the support you received in relation to your caring role / <given name of service>]?</p> <hr/> <hr/> <p>→ INT: Got to question 7</p>

7.	<p>To be able to better understand your answer given in the last question, could you please tell us what the monthly net income of your household is? (Net income is the income of all household members, regardless of source, less taxation and compulsory insurance).</p>					
	<p>Less than 1200 €</p> <p><input type="checkbox"/> [1]</p>	<p>Between 1200 and 2000 €</p> <p><input type="checkbox"/> [2]</p>	<p>Between 2000 and 4000 €</p> <p><input type="checkbox"/> [3]</p>	<p>More than 4000 €</p> <p><input type="checkbox"/> [4]</p>	<p>I don't know → <i>INT</i>: go to question 8</p> <p><input type="checkbox"/> [8]</p>	<p>I would rather not tell → <i>INT</i>: go to question 8</p> <p><input type="checkbox"/> [9]</p>
8.	<p>If you do not know the exact amount, or do not want to reply to this question, could you tell us which of the following statements best describes your current financial situation?</p>					
	<p>Things are very difficult</p> <p><input type="checkbox"/> [1]</p>	<p>I have trouble making ends meet</p> <p><input type="checkbox"/> [2]</p>	<p>I have to be careful but I get by</p> <p><input type="checkbox"/> [3]</p>	<p>Comfortable</p> <p><input type="checkbox"/> [4]</p>	<p>Very comfortable</p> <p><input type="checkbox"/> [5]</p>	<p>Don't know or would rather not tell</p> <p><input type="checkbox"/> [9]</p>