Ref. Ares(2022)2285476 - 29/03/2022

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Grant Agreement No. 875215.

HORIZON 2020
The Framework Programme for Research and Innovation

Project acronym: VALUECARE
Grant Agreement Number: 875215
Project full title: Value-based methodology for integrated care supported by ICT
Call identifier: H2020-SC1-DTH-11-2019

# D2.2 Identify data needed

| | |
|---|---|
| Version: | 2.0 |
| Status: | Revised final |
| Dissemination Level: | Public |
| Due date of deliverable: | 31.05.2021 |
| Actual submission date: | 31.05.2021 and revised 03.02.2021 |
| Project officer: | Elisa Irlandese |
| Work Package: | WP2 Development of new integrated care built on value-based methodology to be implemented at EU level |
| Lead partner for this deliverable: | EMC |
| Partner(s) contributing: | ISRAA, UVEG, MEDRI, UCD, AMC, CDC, FBK, VI, VIDAVO, AFIC |

Main author(s):

| | | | |
|---|---|---|---|
| Esmée Bally | EMC | Amy van Grieken | EMC |

Contributing author(s):

| | | | |
|---|---|---|---|
| Denis Juraga | MEDRI | Maite Ferrando | KVC |
| Oscar Zanutto | ISRAA | Suzanne van den Toren | EMC |
| Athanasios Koumparos | VI | Anastasios Rentoumis | AFIC |
| Oscar Mayora | FBK | Natália Machado | CDC |
| Racheal Dix | LAS NAVES | Andrew Darley | UCD |
| Hein Raat | EMC | | |

Reviewers:

| | | | |
|---|---|---|---|
| Elena Procaccini | AULSS2 | Nancy Karanasiou/ Panos Athanasiadis | VIDAVO |

**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This deliverable contains original unpublished work except where clearly indicated otherwise.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 to through appropriate citation, quotation or both.

## History

| Date | Version number | Change |
|---|---|---|
| 01.05.2021 | 0.1 | Final draft sent to partners for internal review |
| 31.05.2021 | 1.0 | Submitted to EC portal |
| 06.12.2021 | 1.01 | Revised by EMC, version sent to pilot sites for input |
| 23.12.2021 | 1.02 | New version with pilot site input integrated |
| 17.01.2022 | 1.03 | Version sent to pilot sites to check changes |
| 20.01.2022 | 1.04 | Version sent to all internal reviewers |
| 03.02.2022 | 2.0 | Version submitted to EC portal |

## EXECUTIVE SUMMARY

This deliverable, **D2.2 Identify data needed**, provides an overview of all data needed in order to respond to the ValueCare approach. The D2.2 provides strategies to enable easier exchange of information between social and health care services performing the ValueCare approach. The requirements to respond to the ValueCare approach and strategies for easier data exchange are linked and cross-referenced to tasks in WP3, WP4, WP5 and WP7. D2.2 aims to identify all administrative (e.g. personal data, socio-demographic data) and clinical information (e.g. health-related data, documentation of care delivery) needed in pilot sites. More specifically, D2.2 defines data collected from self-reported questionnaires, clinicians, administrative sources and the ValueCare technical solution. D2.2 is a handy resource for partners in order to establish their data flows and infrastructure and support implementation and evaluation of the ValueCare approach.

## TABLE OF CONTENTS

EXECUTIVE SUMMARY ..... 3
1 Introduction to the ValueCare project ..... 6
1.1 Objectives of the project ..... 6
2 Introduction to the deliverable ..... 8
2.1 Deliverable objectives and scope ..... 8
2.2 Relation to other WPs and deliverables ..... 8
3 Methodology ..... 10
3.1 Identify all data needed ..... 10
3.2 Strategies to support easier data exchange between health and social care services ..... 10
4 Results ..... 11
4.1 Identify data needed ..... 11
4.1.1 Administrative data ..... 11
4.1.2 Health, wellbeing and clinical data ..... 16
4.1.3 Pilot-site specific data ..... 19
4.1.4 Timeline ..... 29
4.2 Data exchange between health and social care services ..... 30
5 Conclusions ..... 32
6 References ..... 33

## LIST OF FIGURES

Figure 1. Timeline of data collection. ..... 30

## LIST OF TABLES

Table 1 Deliverable 2.2 in relation to other WPs and deliverables ..... 8
Table 2 Administrative data from older people collected in pilot sites. ..... 11
Table 3. Administrative data from the informal care provider collected in pilot sites. ..... 13
Table 4. Administrative information from formal care providers collected in pilot sites ..... 14
Table 5. Clinical information of older person collected in pilot sites. ..... 16
Table 6. Data collected in Informal care providers ..... 18
Table 7. Data collected in Formal care providers ..... 18
Table 8. Pilot-specific data collected during ValueCare implementation in Athens. ..... 19
Table 9. Pilot-specific data collected during ValueCare implementation in Coimbra. ..... 22
Table 10. Pilot-specific data collected during ValueCare implementation in Cork/Kerry. ..... 24
Table 11. Pilot-specific data collected during ValueCare implementation in Rijeka. ..... 24

Table 12. Pilot-specific data collected during ValueCare implementation in Rotterdam..... 26
Table 13 Pilot-specific data collected during ValueCare implementation in Treviso. ..... 27
Table 14. Pilot-specific data collected during ValueCare implementation in Valencia. ..... 28

# 1 Introduction to the ValueCare project

Healthy ageing along with independent living have become fundamental challenges for Europe as all EU member states (and virtually every country in the world) are experiencing growth in the number and proportion of older persons in their population. Several international organisations (Council of Europe, 2014; International Longevity Centre Brazil, 2014; WHO, 2002) have remarked the importance of the independence, participation and autonomy of older people to remain healthy and, consequently, to ensure their quality of life.

The WHO defines health as "...a state of complete physical, mental and social well-being and not merely the absence of disease". The idea of health as the absence of disease has long been considered insufficiently broad and not covering all aspects of health. Unfortunately, it is at present likely unobtainable for many, particularly with the rise in chronic disease and an aging population, with many people with multi-morbidity and frailty who require a coordinated care plan involving numerous health providers, social and other care services. The concept of health promoted by WHO is also hard to measure, is not tailored to the individual and, according to some authors, of limited use for assessing whether a health system is providing value to citizens. Greater acknowledgment of areas of wellbeing providing wider value to older people and those with chronic illnesses, such as societal participation and coping capacity, may allow for a more practical and thorough assessment of value in healthcare, particularly in high-income countries. Shilton et al. (2011) propose a definition of health focused on giving people the income, education, and power to control their lives, highlighting the role of supportive systems, environments, and policies in enabling health.

In this context, ValueCare's vision of healthy ageing is that any older individual in society can live the best life possible according to what they value, facilitated by access to high quality, person-centred, evidence-based and affordable health and social care services, supported by strong and integrated health and social services. ValueCare partners believe that taking an "enhanced value-based approach" (including not only health but also lifestyle and social care in the concept of value-based care) supported by secure and robust digital technologies will help to achieve this. In addition, the project will also take into account the job satisfaction and the wellbeing of the health and social service providers. Not only satisfying the Triple Aim; i.e. (i) improving the experience of care (including quality and satisfaction); (ii) improving the health of populations; and (iii) containing and potentially reducing, by means of a better use of the available resources, the per capita cost of care, which mainly focuses on the person's side, but taking also into account the care providers and integrating their satisfaction in the job and wellbeing in order to truly optimize ValueCare's performance.

## 1.1 Objectives of the project

ValueCare addresses Horizon 2020 Call: SC1-DTH-2018-2020 – Digital transformation in Health and Care. The project aims to deliver personalised integrated (health and social) care services, better outcomes for citizens, improved care experience, improved staff satisfaction and greater efficiency in the use of resources and coordination of care in a setting that ensures trust of users and policy makers with regard to data access, protection and sharing and which can be replicated and deployed at large scale in other EU countries. In alignment with the above, ValueCare will focus on the following general objectives:

- Objective 1. To deliver efficient outcome-based integrated (health and social) care to older people suffering from cognitive impairment, frailty and multiple chronic health conditions in order to improve their quality of life (and of their families)
- Objective 2. To contribute to the sustainability of health and social care systems in Europe
- Objective 3. To provide a secure, scalable and robust digital solution for integrated care

# 2 Introduction to the deliverable

This deliverable is part of Work Package (WP) 2. The main objective of WP 2 is to develop new value-based social and health integrated care supported by ICT that promotes older persons' goals and the working conditions of professionals. WP2 has the following specific objectives:

- To define a new model of personalised integrated care based on a value-based approach.
- To involve end-users in the creation process.
- To improve quality of life of older people and their families as well as improving the working conditions of health and social care professionals.
- To ensure the recruitment of end-users for the ValueCare approach co-design.

## 2.1 Deliverable objectives and scope

The purpose of deliverable 2.2 (D2.2) is to identify all data needed to perform the ValueCare approach and to explore the potential of using a common ontology for data exchange.

Firstly, to identify all data needed the ValueCare approach entails outcome-based integrated (health and social) care to older people suffering from cognitive impairment, frailty and multiple chronic health conditions in order to improve their quality of life (and of their families). This D2.2 describes the data needed to perform the ValueCare approach, including both the implementation and evaluation of the ValueCare approach. Data needed includes administrative data and clinical data, and pilot-site specific data.
Secondly, the ValueCare approach entails the exchange of data between health and social care services in order to provide optimal patient care. There are several methods to support data exchange. One of them is to use a common ontology for data exchange for patient, clinicians and researchers. This D2.2. provides an overview of data exchange strategies for the ValueCare approach.

D2.2 has the following objectives:

- Identify all data needed; the minimum data needed to respond to the ValueCare approach and provide a timeline of the required data.
- Provide strategies for easier exchange of the identified data needed between health and social care services in the ValueCare approach.

## 2.2 Relation to other WPs and deliverables

This Deliverable is relevant to WP3 for the development of the ICT solution. Furthermore, the data identified in D2.2 supports implementation in pilot sites (WP4) the outcomes measured for evaluation (WP5) and the feasibility study (WP7). It also relates to the data management and ethics (WP8 and WP9). See Table 1.

**Table 1** Deliverable 2.2 in relation to other WPs and deliverables.

| WP | Deliverable /Task | Relationship |
|---|---|---|
| WP3 | Task 3.1 | VALUECARE Digital Solution Architecture Definition and Design (Leader: VIDAVO) |

| | | |
|---|---|---|
| | Task 3.2 | Definition and development of ML/AI algorithms for VALUECARE implementation and Prediction modelling techniques in pilot sites (Leader: FBK) |
| | Task 3.3 | ValueCare digital solution back-end development (leader: FBK) |
| | Task 3.4 | Development of the ValueCare digital solution front-end to enable the ValueCare methodology implementation in pilot sites (leader: VI) |
| WP4 | Task 4.1 | General framework for the pilots' implementation (leader: EMC) |
| | Task 4.3 | ValueCare implementation (leader: MEDRI) |
| WP5 | Task 5.1 | Design of the evaluation framework (leader: EMC) |
| | Task 5.2 | Formative evaluation (Leader: EMC) |
| | Task 5.3 | Summative evaluation (Leader: EMC) |
| | Task 5.4 | Study visits (Leader: EMC) |
| WP7 | Task 7.2 | Business models and corresponding feasibility studies (leader: ECHA) |
| | Task 7.5 | Standardisation activities (leader: KVC) |
| WP8 | Task 8.1 | Ethics management (Leader: UVEG) |
| | Task 8.3 | Data gathering, saving and sharing (Leader: FBK) |
| WP9 | D 9.5 | POPD - Requirement No. 11 (Leader: EMC) |

# 3 Methodology

## 3.1 Identify all data needed

In order to identify the data needed to respond to the ValueCare approach (i.e. implementation and evaluation) the following methods were used. First, information was collected from the evaluation framework (D5.1). This includes including the qualitative and quantitative data collection (e.g. interviews, observations, questionnaires and data collected through the ValueCare Technical Solution). Second, pilot sites provided specific information about the data they intend to collect in order to implement Personalised Care Plans among their participants.

In order to specify between different types of data collected, among different target groups the following categorisation and presentation is used.

**Administrative (i.e. clerical) data** comprises all on personal data (but excluding data specifically about health or social care, and clinical information), record keeping, appointments, coordination and systems for guaranteeing the communication within teams and services and with key persons outside the organisation (meetings, calls, etc.). It also contains information about socio-demographics (e.g. education level).

**Health, well-being and clinical data** consists of data ranging from determinants of health and measures of health (risks) and wellbeing to documentation of care delivery. It also contains information about the implementation and delivery of the ValueCare approach in order to continuously improve care.

**Pilot-site specific data** includes data collected per pilot site target group to implement the ValueCare approach. This can be data collected as part of the ValueCare technical solution (i.e., the ValueCare app or web application), pilot-specific clinical or administrative information, and patient-reported information.

A timeline for data collection is provided, combining the different data collection flows into a figure.

## 3.2 Strategies to support easier data exchange between health and social care services

Linking to the requirements and the activities performed in WP3, Wp4, WP5 and D7.5 an overview is provided of strategies for easier exchange of the identified data needed in the ValueCare approach.

# 4 Results

## 4.1 Identify data needed

### 4.1.1 Administrative data

Table 2 describes the administrative information that is collected in all pilot sites. This includes personal data, administrative data, and relevant socio-economic and demographic information. Self-reported data will be collected from older people (≥65 years of age), their informal caregiver (e.g., family member, neighbour, friend) and health and social care professionals (i.e., formal caregiver). In table 2, 3 and 4 the data collected among each of these groups is presented.

Table 2 **Administrative data from older people collected in pilot sites.**

| | Definition | Supporting information | Source | Type |
|---|---|---|---|---|
| **Administration and registration** | | | | |
| Participant ID | Indicate the participant record number | A separate participant identification folder is created to ensure pseudo-anonymization as part of the research study. | N/A | N/A |
| Name | First name | Information is used to contact patient. | Self-reported (informed consent or from clinical administration system) | Single answer |
| Surname | Last name | Information is used to contact patient. | Self-reported (informed consent or from clinical administration system) | Single answer |
| E-mail account | E-mail address of participant | Information is used to contact patient. | Self-reported (informed consent or from clinical administration system) | Single answer |
| Telephone number | Contact telephone number | Information is used to contact patient. | Self-reported (informed consent or from clinical administration system) | Numerical value |
| Date | Date of completing questionnaire | N/A | Self-reported (questionnaire, all forms) | DD/MM/YYYY |
| Proxy reporting | Indicate whether a caretaker reported items on behalf of the patient | N/A | Self-reported (questionnaire, all forms) | Single answer |
| **Social-demographic information** | | | | |
| Age | Age in years | N/A | Self-reported (questionnaire, baseline) | Numerical value |

| | | | | |
|---|---|---|---|---|
| Sex | Sex at birth | N/A | Self-reported (questionnaire, baseline) | Single answer |
| Migration background | Participant indicates in which country he/she was born and his/her parents | Varies by county and should be determined by country. | Self-reported (questionnaire, baseline) | Single answer |
| Marital status | What is your marital status? | N/A | Self-reported (questionnaire, baseline) | Single answer |
| Living status | Which statement best describes your living arrangement? | N/A | Self-reported (questionnaire, all forms) | Single answer |
| Education level | Highest attained education | Based upon the International Standard Classification of Education (ISCED). | Self-reported (questionnaire, baseline) | Single answer |
| Household income 1 | Approximately how much is your net monthly household income? | N/A | Self-reported (questionnaire, baseline and follow-up) | Single answer |
| Household income 2 | Which kind of income did your household receive in the past year? | N/A | Self-reported (questionnaire, baseline and follow-up) | Single answer |
| Employment status | Do you receive any income from work? | N/A | Self-reported (questionnaire, baseline and follow-up) | Single answer |
| Working hours | How many hours a week do you work? | N/A | Self-reported (questionnaire, baseline) | Single answer |
| **Care use information *(if applicable)*** | | | | |
| Date of index admission | Date of admission for index event. | N/A | Administrative data | Date by DD/MM/YYYY |
| Date of discharge | Did the acute inpatient care or post-acute care include dedicated rehabilitation? | Dedicated rehabilitation during acute inpatient care or post-acute care, either hospital based or outpatient/home based. | Administrative data | Single answer |
| Discharge destination | What type of place was the patient discharged to? | N/A | Administrative data | Single answer |
| **Administrative ValueCare app information** | | | | |
| Username | The participant's username to sign in to the ValueCare app | N/A | N/A | N/A |
| Password (known only to participant) | The participant's password to sign in to the ValueCare app | N/A | N/A | N/A |
| Language choice | Preferred language by the ValueCare app. | N/A | Automatic | |

| | | | | |
|---|---|---|---|---|
| Notification/ coaching preferences | Notification and feedback preferences of the participant. | N/A | Predefined | |

Table 3. **Administrative data from the informal care provider collected in pilot sites.**

| | Definition | Supporting information | Source | Type |
|---|---|---|---|---|
| **Administration** | | | | |
| Participant ID | Indicate the participant record number. | A separate participant identification folder will be created to ensure pseudo-anonymization as part of the research study. | N/A | N/A |
| Name | First name | N/A | Self-reported (informed consent) | Single answer |
| Surname | Last name | N/A | Self-reported (informed consent) | Single answer |
| E-mail account | E-mail address of participant. | Information is used to contact carer. | Self-reported (informed consent or intake) | Single answer |
| Telephone number | Contact telephone number. | Information is used to contact carer. | Self-reported (informed consent or intake) | Numerical value |
| Date | Date of completing questionnaire. | N/A | Self-reported (questionnaire, all forms) | DD/MM/YYYY |
| **Social-demographic and socio-economic information** | | | | |
| Age | Age in years. | N/A | Self-reported (questionnaire, baseline) | Numerical value |
| Sex | Sex at birth. | N/A | Self-reported (questionnaire, baseline) | Single answer |
| Migration background | Participant indicates in which country he/she was born and his/her parents. | Varies by county and should be determined by country. | Self-reported (questionnaire, baseline) | Single answer |
| Marital status | What is your marital status? | N/A | Self-reported (questionnaire, baseline) | Single answer |
| Household composition | What is your household composition? | N/A | Self-reported (questionnaire, baseline and follow-up) | Single answer |
| Education level | Highest attained education | Based upon the International Standard Classification of Education (ISCED). | Self-reported (questionnaire, baseline) | Single answer |

| | | | | |
|---|---|---|---|---|
| Household income 1 | Approximately how much is your net monthly household income? | N/A | Self-reported (questionnaire, baseline and follow-up) | Single answer |
| Household income 2 | Which kind of income did your household receive in the past year? | N/A | Self-reported (questionnaire, baseline and follow-up) | Single answer |
| Employment status | Do you receive any income from work? | N/A | Self-reported (questionnaire, baseline and follow-up) | Single answer |
| Working hours | How many hours a week do you work? | N/A | Self-reported (questionnaire, baseline) | Single answer |
| **Administrative information for the ValueCare informal care provider dashboard** | | | | |
| Username | The participant's username to sign in to the ValueCare dashboard. | N/A | N/A | N/A |
| Password (known only to participant) | The participant's password to sign in to the ValueCare dashboard. | N/A | N/A | N/A |
| Language choice | Preferred language by the ValueCare dashboard user. | N/A | Automatic/ chosen | Single answer |

Table 4. **Administrative information from formal care providers collected in pilot sites**

| | Definition | Supporting information | Source | Type |
|---|---|---|---|---|
| **Administration** | | | | |
| Participant ID | Indicate the participant record number. | A separate participant identification folder will be created to ensure pseudo-anonymization as part of the research study. | N/A | Numerical value |
| Name | First name | N/A | Self-reported | Single answer |
| Surname | Last name | N/A | Self-reported | Single answer |
| E-mail account | E-mail address of participant. | N/A | Self-reported | Single answer |

| | | | | |
|---|---|---|---|---|
| Telephone number (if applicable) | Contact telephone number. | Information is used for the patient to contact the care provider. | General hospital information. | Numerical value |
| Date | Date of completing questionnaire. | N/A | Self-reported (questionnaire, all forms) | DD/MM/YYYY |
| **Social-demographic information** | | | | |
| Age | Age in years. | N/A | Self-reported (questionnaire, baseline) | Numerical value |
| Sex | Sex at birth. | N/A | Self-reported (questionnaire, baseline) | Single answer |
| Migration background | Participant indicates in which country he/she was born and his/her parents. | Varies by county and should be determined by country. | Self-reported (questionnaire, baseline) | Single answer |
| Education level | Highest attained education. | Based upon the International Standard Classification of Education (ISCED). | Self-reported (questionnaire, baseline) | Single answer |
| Working hours | What are your working hours? | N/A | Self-reported (questionnaire, baseline) | Single answer |
| Work setting 1 | Which setting do you spend most time in? | N/A | Self-reported (questionnaire, baseline) | Single answer |
| Work setting 2 | Which statement best describes your staff group? | N/A | Self-reported (questionnaire, baseline) | Single answer |
| **ValueCare dashboard information** | | | | |
| Username | The participant's username to sign in to the ValueCare dashboard. | N/A | N/A | Single answer |
| Password (known only to participant) | The participant's password to sign in to the ValueCare dashboard. | N/A | N/A | Single answer |
| Language choice | Preferred language by the ValueCare dashboard user. | N/A | Automatic | |
| Notification preferences | Notification and feedback preferences of the participant. | N/A | Automatic | |

### 4.1.2 Health, wellbeing and clinical data

Table 5 describes the health, wellbeing and clinical information collected in all pilot sites. This includes determinants of health, measures of health (risks) and wellbeing, and care delivery information. These outcomes measures are mostly self-reported by the target groups including patients, informal caregivers and health and social professionals (formal care providers).

Table 5. **Clinical information of older person collected in pilot sites.**

| What? | How? | Definition | Supporting definition | Source | Type |
|---|---|---|---|---|---|
| Diagnosis (pilot site specific- see later tables) | N/A | Indicate diagnosis made. | N/A | Clinical assessment, self-report | Single answer |
| Health-related quality of life 1 | PROMIS-10 Global Health | Assessment of general domain of health and functioning. | N/A | Self-reported (baseline and follow-up) | Single answer |
| Health-related quality of life 2 | EQ-5D-5L | Assessment of general domain of health and functioning. | N/A | Self-reported (baseline and follow-up) | Single answer |
| Frailty stage | Tilburg Frailty Indicator | Asses frailty stage using the Tilburg Frailty Indicator. | N/A | Self-reported (baseline and follow-up) | Single answer |
| Comorbidities | ICHOM Older Person Set | Have you ever been told by a doctor that you have any of the following conditions? | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003) | Self-reported (baseline and follow-up) | Multiple answers |
| Loneliness | UCLA-3-item scale | Measures extent to which someone is lonely and isolated. | Based upon the UCLA Loneliness Scale (Hughes et al., 2004) | Self-reported (baseline and follow-up) | Single answer |
| Activities of daily living functioning | Modified Barthel index | ADL using the modified Barthel Index (SELFY-MPI) | Total score | Self-reported (baseline and follow-up) | Single answer |
| Falls | FES-I and VAS FOF | Amount of falls and fear of falling. | Based upon the Visual Analogue Scale for Fear of Falling (VAS-FOF) (Scheffer et al., 2010) and Falls Efficacy Scale-International (FES-I) (Yardley et al., 2005) | Self-reported (baseline and follow-up) | Numerical value, single answer |
| Body mass index | ICHOM Older Person Set | Height and weight are used to calculate BMI. | N/A | Self-reported (baseline and follow-up) | Numerical value |

| | | | | | |
|---|---|---|---|---|---|
| Smoking status | ICHOM Older Person Set | Do you smoke cigarettes (or cigars, cigarillos, tobacco, or pipes) at the present time? | N/A | Self-reported (baseline and follow-up) | Single answer |
| Alcohol use | ICHOM Overall Adult Health Set | How often alcohol is consumed and how many standard drink on a typical day. | N/A | Self-reported (baseline and follow-up) | Single answer |
| Physical activity 1 | IPAQ | Assessment of sitting time. | Based upon the International Physical Activity Questionnaire (Lee et al. 2011) | Self-reported (baseline and follow-up) | Numerical value |
| Physical activity 2 | SHARE-FI | Assessment of intensity of physical activity. | Based upon the Survey of Health, Ageing and Retirement in Europe (Romero-Ortuno et al. 2010) | Self-reported (baseline and follow-up) | Single answer |
| Nutrition | SNAQ65+ | Determining (the risk of) undernutrition using Short Nutritional Assessment Questionnaire 65+ (SNAQ65+). | N/A | Self-reported (baseline and follow-up), clinical | Single answer, numerical value |
| Poly-pharmacy | MRQ-10 | Usage of medication and appropriate medication use. | N/A | Self-reported (baseline and follow-up) | Single answer |
| Care use 1 | SMRC Health Care Utilisation questionnaire | Have you seen a medical doctor at any time during the past 12 months? | All appointments with healthcare professionals. | Self-reported (baseline and follow-up) | Number of appointments |
| Care use 2 | SMRC Health Care Utilisation questionnaire | Due to your health, have you received help in household activities in the past 12 months? | N/A | Self-reported (baseline and follow-up) | Hours per week and amount of weeks |
| Care use 3 | SMRC Health Care Utilisation questionnaire | Have you received help in caring for yourself in the past 12 months? | Help received from informal or formal caregiver(s). | Self-reported (baseline and follow-up) | Hours per week and amount of weeks |
| Care use 4 | SMRC Health Care Utilisation questionnaire | Have you been admitted to a hospital during the past 12 months? | N/A | Self-reported (baseline and follow-up) | Single answer |
| Productivity losses | iPCQ | Assessment of the productivity lossess. | Based upon the iMTA Productivity Cost Questionnaire (iPCQ) (Bouwmans et al., 2015) | Self-reported (baseline and follow-up) | Numerical value, single answer |
| **Information about care delivery: the implementation of the ValueCare approach** | | | | | |
| Evaluation of care delivery | Evaluation of care delivery in terms of usability, | Information for improvement of the ValueCare approach. | N/A | Self-reported (ValueCare app, questionnaire | Mixed methods |

| | | | | | |
|---|---|---|---|---|---|
| | feasibility and appreciation | | | s), interviews with a selection of end-users | |

Table 6. **Data collected in Informal care providers**

| Variable | Measurement instrument | Definition | Supporting definition | Source | Type |
|---|---|---|---|---|---|
| Health related quality of life 1 | PROMIS-10 Global Health | Assessment of general domains of health and functioning. | N/A | Self-reported (baseline and follow-up) | Single answer |
| Carer burden | 4-item Zarit Burden Interview | Carer reported burden. | N/A | Self-reported (baseline and follow-up) | Single answer |
| Autonomy and control | ICHOM Older Person Set | Which of the following statements best describes how much control you have over your daily life? | Question from the Adult Social Care Outcomes Toolkit | Self-reported (baseline and follow-up) | Single answer |
| Time spent in activities to care for patient | iVICQ | Assessment of the impact of informal caregiving. | Based upon the iMTA Valuation of Informal Care Questionnaire (iVICQ) (Hoefman et al., 2013) | Self-reported (baseline and follow-up) | Hours per week over the last week |
| Productivity losses | iPCQ | Assessment of the productivity lossess. | Based upon the iMTA Productivity Cost Questionnaire (iPCQ) (Bouwmans et al., 2015) | Self-reported (baseline and follow-up) | Numerical value, single answer |
| **Information about care delivery: the implementation of the ValueCare approach** | | | | | |
| Evaluation of care delivery | Evaluation care delivery in terms of usability, feasibility and appreciation | Information for improvement of the ValueCare approach. | N/A | Self-reported (ValueCare dashboard, questionnaire s), yearly interviews with a selection of patients | Mixed methods |

Table 7. **Data collected in Formal care providers**

| Variable | Measurement instrument | Definition | Supporting definition | Source | Type |
|---|---|---|---|---|---|
| Health related quality of life 1 | PROMIS-10 Global Health | Assessment of general domains of health and functioning. | N/A | Self-reported (baseline and follow-up) | Single answer |

| | | | | | |
|---|---|---|---|---|---|
| Working environment | Culture of Care Barometer | Assessment of working environment and job satisfaction | N/A | Self-reported (baseline and follow-up) | Single answer |
| Job satisfaction | Minnesota Satisfaction Questionnaire | Assessment of satisfaction with various aspects of the job. | N/A | Self-reported (baseline and follow-up) | Single answer |
| Work-related burnout | Copenhagen burnout inventory | Assessing work-related burnout. | N/A | Self-reported (baseline and follow-up) | Single answer |
| **Information about care delivery: the implementation of the ValueCare approach** | | | | | |
| Evaluation of care delivery | Evaluation of care delivery in terms of usability, feasibility and appreciation | Information for improvement of the ValueCare approach. | N/A | Self-reported (ValueCare app, questionnaires), interviews with a selection of end-users | Mixed methods |

### 4.1.3 Pilot-site specific data

Tables 8-14 describe the pilot-specific information collected during the implementation of the ValueCare approach. This includes clinical information, patient-reported information and information gathered in the ValueCare app, through wearables or by the ValueCare web application. How pilot sites obtain the data from sources and enable data exchange is in the domain of the pilot site and will be specified in the local plan for implementation.

Each pilot site provides details on the following elements of data collection.

- **What?** General description of the data that is collected. Examples include: disease-specific assessments (e.g. MCI, Stroke), lifestyle behaviours (e.g. nutrition, physical activity, sleep), or social behaviour (e.g. interactions).
- **Why?** Purpose of the data collection. Examples include: in- or exclusion criteria, awareness/motivation, or monitoring.
- **How?** How the data is collected. Examples include: food diary data, steps, calories etc.
- **By whom/what?** The source of the data. Examples include: clinical assessment, ValueCare app data, or wearable data.
- **Data type?** The type of data collected. Examples include: self-report, numerical, or app-data.

Table 8. **Pilot-specific data collected during ValueCare implementation in Athens.**

| What? | Why? | How? | By whom/what? | Data type? |
|---|---|---|---|---|
| **Older person** | | | | |
| **ICHOM Standard set diabetes** | | | | |

| | | | | |
|---|---|---|---|---|
| Diabetes control | Glycaemic control: HbA1c and Time-in-range. Time in range is only measured for persons with diabetes who already have access to continuous glucose monitoring as part of their care | Clinician/ self-report | Questionnaire baseline, 12m, 18m | Numerical |
| | Intermediate Outcomes: Includes disease management goals such as blood pressure, lipid profile, and body mass index | Clinician/ self-report | Questionnaire baseline, 12m, 18m | Numerical |
| Acute events | Diabetic Ketoacidosis and Hyperosmolar Hyperglycemic Syndrome | Clinician/ self-report | Questionnaire baseline, 12m, 18m | Numerical |
| | Hypoglycemia | Clinician/ self-report | Questionnaire baseline, 12m, 18m | Numerical |
| | Acute Cardiovascular Events (Stroke and Myocardial Infarction) | Clinician/ self-report | Questionnaire baseline, 12m, 18m | Numerical |
| | Lower Limb Amputation | Clinician/ self-report | Questionnaire baseline, 12m, 18m | Numerical |
| Chronic Complications | See ICHOM Diabetes set | Clinician/ self-report | Questionnaire baseline, 12m, 18m | Numerical |
| Psychological Wellbeing | Captured using WHO (Five) WellBeing Index (WHO-5) | Self-reported | Questionnaire baseline, 12m, 18m | Numerical |
| Diabetes Distress | Captured using Problem Areas in Diabetes Questionnaire (PAID) | Self-reported | Questionnaire baseline, 12m, 18m | Numerical |
| Depression | Captured using Patient Health Questionnaire (PHQ-9) | Self-reported | Questionnaire baseline, 12m, 18m | Numerical |
| Hospitalization | Hospitalization Admission date | Self-reported | Questionnaire baseline, 12m, 18m | DD/MM/YYYY |
| | Hospitalization Discharge date | Self-reported | Questionnaire baseline, 12m, 18m | DD/MM/YYYY |

| | | | | |
|---|---|---|---|---|
| | Hospitalization Discharge Diagnosis | Self-reported | Questionnaire baseline, 12m, 18m | Multiple Answers |
| | Emergency Room Utilization | Self-reported | Questionnaire baseline, 12m, 18m | Numerical |
| **Input for and compliance with the care plan** | | | | |
| Blood pressure | Systolic blood pressure2 | Systolic reading of blood pressure, as measured by the indicated device type in mm/Hg (daily) | ValueCare app | Numerical |
| | Diastolic blood pressure2 | Diastolic reading of blood pressure, as measured by the indicated device type in mm/Hg (daily) | ValueCare app | Numerical |
| Blood glucose | Blood Glucose | Reading of blood glucose, as measured by the indicated device type in mg/dL (daily) | ValueCare app | Numerical |
| Falls | Falls Detection | Falls diary (monthly) | ValueCare app | Numerical |
| Heart Rate | | Reading of heart contractions or beats per unit of time (daily) | Activity Tracker | Numerical |
| Physical activity | Type of PA | Set and assess qualitatively aerobic, flexibility, balance and strength exercise levels (every 3 months) | ValueCare app<br>Activity Tracker | Multiple answers |
| | Duration of PA | Set goals and assess goal achievement (weekly) | ValueCare app<br>Activity Tracker | Minutes |
| | Awareness of PA | Videos on physical activity viewed (weekly) | ValueCare app | Numerical |
| Nutrition | Awareness | Videos on healthy recipes viewed (weekly) | ValueCare app | numerical |
| | Awareness/ compliance | Consumption of food groups for Mediterranean diet | Self-report | Portions |

| | | | | |
|---|---|---|---|---|
| | | adoption (per day/week) | | |

Table 9. **Pilot-specific data collected during ValueCare implementation in Coimbra.**

| What? | Why? | How? | By whom/what? | Data type? |
|---|---|---|---|---|
| **Older person** | | | | |
| **Inclusion criteria** | | | | |
| Clinical assessment of general health | Inclusion or exclusion of participant | Assessment - ICHOM | Clinical assessment/ self-report | Numerical |
| **Compliance with and input for the care plan** | | | | |
| Nutrition | Care plan definition | Assessment with nutritionist | Interview/ questionnaire/ online tool | N/a |
| Nutrition | Awareness and motivation | Assessment of nutrition awareness (once a month) | ValueCare app/ self-report | Numerical |
| Nutrition | Support | Suggestion about healthy data | ValueCare app | N/A |
| Nutrition | Monitoring | Number of videos related with healthy eating in older age seen. | ValueCare app | Numerical value |
| Nutrition | | Number of meals eaten (daily). | ValueCare app/ self-report | Diary - single answer |
| Nutrition | | Water intake (daily). | ValueCare app/ self-report | Diary - multiple answers |
| Physical activity | Care plan definition | Assessment with physiotherapist | Interview/ questionnaire/ online tool | N/a |
| Physical activity | Awareness and motivation | Assessment of physical activity awareness (once a month) | ValueCare app/ self-report | Numerical |
| Physical activity | Support | Suggestion about physical activity | ValueCare app | N/A |

| | | | | |
|---|---|---|---|---|
| Physical activity | Monitoring | Duration of physical activity (minutes per week). | ValueCare app (manually) | Exercise data |
| | | Type of activity (aerobic exercise, strength training, flexibility, balance). | ValueCare app / self-report | Exercise data |
| | | Number of recommended videos seen on physical exercise (weekly). | ValueCare app | Numerical value |
| Cognitive functions | Care plan definition | Assessment with psychologist | Interview/ questionnaire/ online tool | N/a |
| Cognitive functions | Support | Suggestion about cognitive stimulation | ValueCare app | N/A |
| Cognitive functions | Motivation | Type of games played (working memory, executive functions, attention, speech). | ValueCare app | App data |
| Cognitive functions | Monitoring | Play time (in minutes). | ValueCare app | App data |
| | | Number of games played. | ValueCare app | App data |
| Social Interaction | Care plan definition | Psychosocial motivational interview | Interview – Loneliness scale/ Questionnaire/ online tool | N/a |
| Social Interaction | Support | Suggestion about social interaction | ValueCare app | N/A |
| Social Interaction | Monitoring | Social Activities Attended / Meet up with relatives or friends (weekly). | ValueCare app (interview)/ self-report | Numerical |
| Emotional wellbeing | Care plan definition | Assessment with phycologist | Interview – Warwick - Edinburgh wellbeing scale | N/a/ numerical |
| Emotional wellbeing | Awareness and motivation | Assessment of phycologist awareness (once a month) | ValueCare app/ self-report | Numerical |
| Emotional wellbeing | Support | Suggestion about emotional wellbeing | ValueCare app | N/A |

| | | | | |
|---|---|---|---|---|
| Emotional wellbeing | Monitoring | Assessment of mood status using a questionnaire (once a week) | ValueCare app, virtual coach/ self-report | Numerical |

Table 10. **Pilot-specific data collected during ValueCare implementation in Cork/Kerry.**

| What? | Why? | How? | By whom/what? | Data type? |
|---|---|---|---|---|
| **Older person** | | | | |
| **Input for and compliance with the care plan** | | | | |
| Nutrition | Care Plan Definition | Comprehensive Geriatric Assessment/ SNAQ65+ | Clinical Team/Baseline Questionnaire | Assessment scores |
| | Monitoring | Meal diary (Daily) | ValueCare app | Diary - multiple answers |
| | | Number of meals eaten (Daily) | ValueCare app | Diary - single answer |
| | | Nutritional intake (according to food pyramid) | ValueCare app - meal diary | Diary - multiple answers |
| | | Number of videos seen with healthy recipes (once a week). | ValueCare app | Numerical value |
| Physical activity | Care plan definition | Assessment of physical abilities and exercise levels using Comprehensive Geriatric Assessment/Tilburg Frailty Indicator/Modified Barthel Index/FES-I and VAS FOF/IPAQ/SHARE FI | Clinical Team/Baseline Questionnaire | Assessment scores |
| | Monitoring | Frequency of physical activity per week | ValueCare app (manually) | Exercise data |
| | | Type of activity (aerobic exercise, strength training, flexibility, balance). | ValueCare app | Questionnaire, exercise data |
| | | Number of recommended videos seen on physical exercise (weekly). | ValueCare app | Numerical value |
| Medication | Care plan definition | Comprehensive Geriatric Assessment/MRQ-10 | Clinical Team/Baseline Questionnaire | Assessment scores |
| | Monitoring | Daily medication adherence reminder (non-specific) | ValueCare app (manually) | Questionnaire |
| Social interaction | Care plan definition | Comprehensive Geriatric Assessment/Tilburg Frailty Index, UCLA-3-Item Scale | Clinical Team/Baseline Questionnaire | Assessment scores |
| | Monitoring | Self-reported number of social activities and meetings with Relatives/Friends/Neighbours (Weekly) | ValueCare app (manually) | Numerical value |
| | | Types of social activities engaged | ValueCare app (manually) | Diary – multiple answers |
| | | Engagement with local services information within app | Dashboard | Interactive data |

Table 11**. Pilot-specific data collected during ValueCare implementation in Rijeka.**

| What? | Why? | How? | By whom/what? | Data type? |
|---|---|---|---|---|
| **Older person** | | | | |

| | | | | |
|---|---|---|---|---|
| **Clinical information** | | | | |
| Allergies | N/A | Is the patient allergic to any food or medication? | Clinical assessment | Single answer |
| **Input for and compliance with the care plan** | | | | |
| Nutrition | Awareness and motivation | Recipe videos or PDF; Q&A/tips regarding nutrition for persons with myocardial infarction. | ValueCare app | Number of views/interactions - Dashboard analytics trend |
| Nutrition | Monitoring | Awareness goal which measured by a 6-item quiz for self-assessment perception (monthly). | ValueCare app (Virtual coach) | Diary - multiple answers |
| Physical activity | Awareness and motivation | Exercise videos or PDF; Q&A/Tips regarding physical activity for persons with myocardial infarction | ValueCare app | Number of views/interactions - Dashboard analytics trend |
| Physical activity | Monitoring | Number of steps during the week | ValueCare app (Virtual coach) | Exercise data - Dashboard analytics trend |
| | | Heart rate | Smartwatch | Heart rate data - Dashboard analytics trend |
| | | Reminder to move | Smartwatch | Notification - Dashboard analytics trend |
| | | Number of steps | Smartwatch | Exercise data - Dashboard analytics trend |
| | | Daily distance covered | Smartwatch | Exercise data - Dashboard analytics trend |
| | | Burned calories. | Smartwatch | Nutrition and exercise data - Dashboard analytics trend |
| Medication | Awareness and motivation | Information on medication and side effects (track whether information, e.g., pdf, was accessed). | ValueCare app | Number of views/interactions - Dashboard analytics trend |
| Medication | Monitoring | Answers to questionnaire on medication intake (name of medication, dosage - number of pills, shape and the colour of the pill, the time and day at which the pill should be taken and duration of therapy) | ValueCare dashboard | Questionnaire |
| | | Intake of medications according to the defined care plan | ValueCare app (Virtual coach) | Questionnaire / notifications |
| Sleep | Monitoring | Quantitative assessment of sleep quality | Smartwatch | Sleep data - Dashboard analytics trend |

| | | | | |
|---|---|---|---|---|
| Interaction with GP, patronage nurses and researchers | Monitoring | Number of text messages, emails, telephone and video calls | ValueCare app (messaging, email, video call) | Interaction data - Dashboard analytics trend |
| Social care rights | Awareness and motivation | Information (PDF) regarding the myocardial infarction patients' rights within the Croatian social care system | ValueCare app | Number of views/interactions - Dashboard analytics trend |

Table 12. **Pilot-specific data collected during ValueCare implementation in Rotterdam.**

| What? | Why? | How? | By whom/what? | Data type? |
|---|---|---|---|---|
| **Older person** | | | | |
| **Clinical assessment** | | | | |
| Date of index admission | Date of admission to hospital for stroke | Administrative information from health record | Administrative data | Date by DD/MM/YYYY |
| Date of discharge | Date of discharge from hospital | Administrative information from health record | Administrative data | Single answer |
| Discharge destination | What type of place was the patient discharged to? | Administrative information from health record | Administrative data | Single answer |
| Stroke type | Indicate stroke severity and type | Clinical assessment | Nurse practitioner | Single answer |
| Prior stroke | Indicate whether a patient has had a stroke prior to this hospitalization | Administrative information from health record | Administrative data | Single answer |
| Stroke recurrence | Report of new stroke after admission for stroke | Administrative information from health record | Administrative data | Single answer |
| Readmission | Report of readmission to hospital after stroke | Administrative information from health record | Administrative data | Single answer |
| Ability to communicate | Assessment of problems with communication or understanding. | Clinical assessment | Nurse practitioner | Single answer |
| **Input for and compliance with the care plan** | | | | |
| Lifestyle information (including nutrition, sleep, | Awareness and motivation/support | Lifestyle information related to rehabilitation after stroke (i.e. | ValueCare app | Number of views/interactions |

| | | | | |
|---|---|---|---|---|
| physical activity, etc.) | | videos, pdfs, recipes and tips) | | |
| Physical activity | Monitoring | Duration of exercise, exercise repetitions, report injuries or complaints. | ValueCare app, Virtual Coach, activity tracker | Exercise data - Trend over time |
| | | Number of steps (weekly) | Activity tracker | Exercise data - Trend over time |
| | | Activity and activity goals reached (weekly) | ValueCare app, Virtual Coach | Single answer - Trend over time |
| Medication | Monitoring | Information on medication (track whether information was accessed). | ValueCare app | Number of interactions |
| | | Reminder to take medication. | ValueCare app | Number of notifications - Trend |
| Emotional well-being | Awareness and motivation | Optional online/ physical training with other patients (e.g. mindfulness) | ValueCare app/ on location | Registration – number of lessons attended |
| | Monitoring | Patient reports mood every three months. | ValueCare app, Virtual Coach | Total score -Trend, |

Table 13 **Pilot-specific data collected during ValueCare implementation in Treviso.**

| What? | Why? | How? | By whom/what? | What? |
|---|---|---|---|---|
| **Older person** | | | | |
| **Inclusion criteria** | | | | |
| Clinical assessment of cognitive impairment | Inclusion or exclusion of participant | Assessment of cognitive functioning using Mini Mental State Examination (MMSE) and Clinical Dementia Rating Scale (CDR) | Clinical | Interview-single answers |
| **Input for and compliance with the care plan** | | | | |
| Nutrition | Support | Suggestions about healthy diet | ValueCare app | N/A |
| Physical activity | Monitoring | Daily active zone minutes | Smart-watch | Exercise data |
| | | Number of steps (daily) | Smart-watch | Exercise data |
| | | Burned calories (daily) | Smart-watch | Exercise data |

| | | | | |
|---|---|---|---|---|
| Sleep | Monitoring | Quantitative assessment of sleep phases (e.g. hours of sleep, REM phases) | Smart-watch | Sleep data |
| Cognitive functions | Games | Type of games played (working memory, executive functions, attention, speech) | ValueCare app | Games data |
| | | Play time (in minutes, when playing) | ValueCare app | Games data |
| Social interaction | Monitoring | Number of incoming and outgoing call (if available) | Smart-phone | Interaction data |
| | | Time of telephone calls | Smart-phone | Interaction data |
| | | Messaging (if available) | Smart-phone | Interaction data |
| Emotional well-being | Monitoring | Assessment of mood status using a questionnaire (once a week) and Mindfulness practices | ValueCare app, virtual coach | Dialogue data |

Table 14. **Pilot-specific data collected during ValueCare implementation in Valencia.**

| What? | Why? | How? | By whom/what? | What? |
|---|---|---|---|---|
| **Older person** | | | | |
| **Inclusion criteria** | | | | |
| Clinical assessment: frailty screening | Inclusion criteria for recruitment | Assessment of frailty using FRAIL Scale, Pfeiffer score for cognitive function, and Barthel for physical state | Clinical assessment | Questionnaire |
| **Input for and compliance with the care plan** | | | | |
| Nutrition | Care plan definition | Protein Screener (Wijnhoven et al., 2018) and SNAQ65+ | Clinical assessment | Questionnaire |
| | Monitoring | Meal diary (daily) | ValueCare app | Diary - multiple answers |
| | | Number of meals eaten daily. | ValueCare app | Diary - single answer - Dashboard analytics trend |
| | | Number of videos seen with healthy recipes (once a week). | ValueCare app | Numerical value |
| | | Monthly weight | ValueCare app (manually) | Numerical value - Dashboard analytics trend |
| Physical activity | Care plan definition | Assessment of physical capacity using Short Physical Performance Battery (SPPB), Tilburg | Clinical assessment | Questionnaire/ online tool |

| | | | | |
|---|---|---|---|---|
| | | Frailty Index, and Barthel Index | | |
| | Monitoring | Frequency of physical activity per week | ValueCare app (manually) | Exercise data |
| | | Type of activity (aerobic exercise, strength training, flexibility, balance). | ValueCare app | Questionnaire, exercise data |
| | | Number of recommended videos seen on physical exercise (weekly). | ValueCare app | Numerical value |
| Social interaction | Care plan definition | Psychosocial motivational interview (Miller & Rose, 2009), Tilburg Frailty Index, UCLA-3 | Clinical assessment | Questionnaire |
| | Monitoring | Social Activities Attended / Meet up with relatives or friends (weekly) | ValueCare app (interview) | Questionnaire |
| Medication | Care plan definition | Medication Risk Questionnaire | | |
| Medication | Monitoring | Track medication use and adherence to medication plan. | ValueCare app | Notification |
| **Informal and formal caregiver** | | | | |
| Medication | Monitoring | Reduction or change in medications. | ValueCare dashboard | Notification |
| | | Compliance with care plan | ValueCare dashboard | |

### 4.1.4 Timeline

The following timeline (Figure 1) provides an indication of when the data is collected. Administrative data is collected at baseline using self-report questionnaires, administrative data and clinician-reported data. Clinical data is collected at set time points (baseline, 12-month follow-up and 18-month follow-up) using self-report questionnaires. Pilot-site specific information is collected in differential time points, using data from the ValueCare technical solution (e.g. activity tracker, smartwatch), clinician-reported or administrative sources.

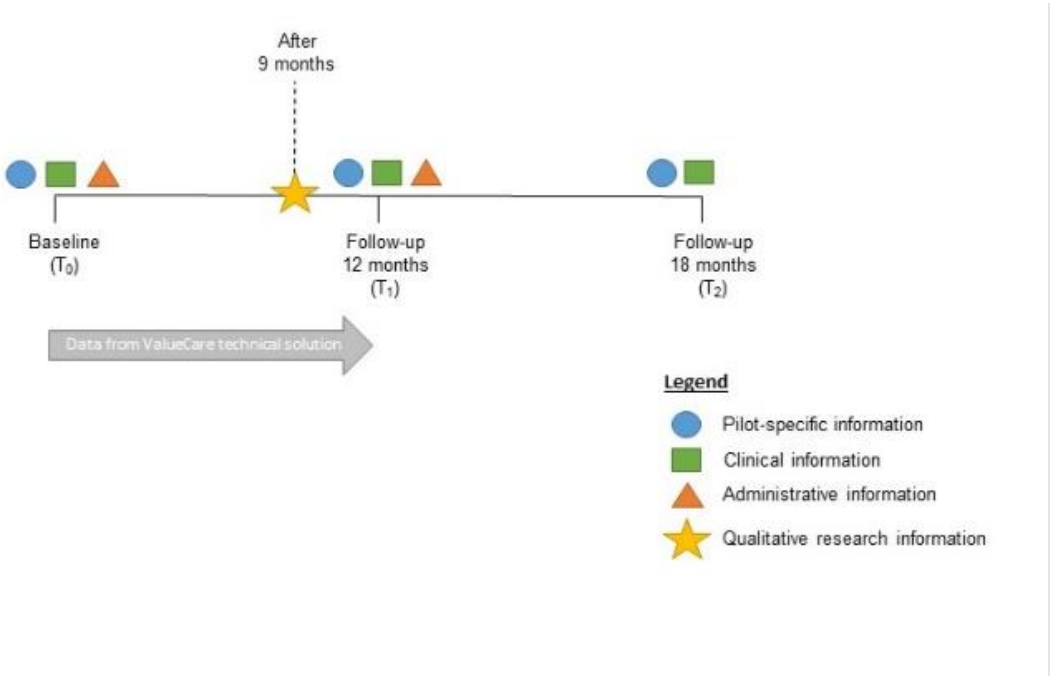


**Figure 1. Timeline of data collection.**

## 4.2 Data exchange between health and social care services

The vision of the ValueCare approach is to support data exchange by using common terminology and common data models.

a) The use of common terminology

The international standard for clinical terminology is SNOMED CT (https://www.snomed.org/). This standard can be used between care providers, in for example the Electronic Health Record, to improve communication and the availability of relevant clinical information. SNOWMED aligns with other international medical classification systems for disease such as the ICD-10. New concepts, descriptions and relationships can be added to the logical model.

At national level the implementation and adoption of SNOMED CT by national and local suppliers of health care and IT need to be supported. For example, in the Netherlands the Nictiz (Dutch National Knowledge Institute on Digital Data Exchange in Care) supports implementation through the SNOMED National Release Center providing licences for free, courses, advice etc. Besides the international classification systems, national guidelines for medical professionals are integrated in the SNOMED CT standard that is implemented in the Netherlands.

b) The use of observational data from different sources by common data models.

The Observational Health Data Sciences and Informatics (OHDSI) community (OHDSI – Observational Health Data Sciences and Informatics) is active in the standardization of databases across the world. They work on the development and adoption of the Common Data Model known as the OMOP Common Data Model. Differential data sources, such as data from an administration system and an Electronic Health Record, can be converted to OMOP and thereafter analytic tools can be used to derive evidence. Evidence can serve different purposes, such as research, insurance claims and other.

A specific application and validation of the OMOP model is done in the EHDEN project. The European Health Data and Evidence Network (EHDEN) is developing the required infrastructure in a federated network at scale across Europe to support health better health decisions, outcomes and care. Through open calls data from different institutions is harmonised according to the OMOP model.

Specifically, the following strategies are suggested for the ValueCare approach to make the exchange of identified needed data between health and social services easier.

1. The use of the ICHOM standard sets to assess Patient Reported Health Outcome Measures

The International Consortium for Health Outcome Measurement (ICHOM) develops and defines global sets of patient-reported outcome measures. By supporting the use of the standard sets value is created for all stakeholders. Health and social outcomes relevant for the patient are assessed in the ValueCare approach.

2. Implementing a Personalised Care Plan

ValueCare uses the ICHOM standard set as starting point to gain insight in health and social outcomes that matter to the patient. The results of the assessment are discussed and a Personalised Care Plan is developed. This care plan integrates the patient-reported outcomes in the more medical health domain (e.g. medical support) as well as social health domain (e.g. social support).

3. Exchange of relevant information in the ValueCare technical solution

The ValueCare technical solution supports the exchange of data by making the results of the assessment using the ICHOM standard sets accessible for all health and social care services. The ValueCare dashboard contains an overview of the results of the assessment. The ValueCare dashboard can be used by health and social service professionals from different organizations.

# 5 Conclusions

The present deliverable **D2.2 Identify data needed** provides an overview of the data needed to respond to the ValueCare approach. It present the strategies used in ValueCare to support easy and fast exchange of these data between social and health care services. More specifically, WP3 can use this deliverable during the development of the ICT solution (Task 3.3 and 3.4). Furthermore, the clerical and clinical data identified in D2.2 supports implementation in pilot sites (WP4). The present deliverable provides input for D7.5 and D7.6. In particular, D7.5 explores how the health and social data managed in ValueCare will contribute to validate existing standard outcome measures (e.g. ICHOMs) while the final conclusions on this issue will be reported in D7.6. The D2.2. also provides input for ethics and data management (WP9 and WP9). Monitoring and evaluation activities (as part of WP5) will provide insight in the minimum dataset needed to respond to the ValueCare approach, reported in the end-term data needed D2.9.

Linking and cross-referencing to the requirements of the ValueCare approach and the various sources of information, including the evaluation framework (D5.1) and data gathered by the ValueCare technical solution (e.g. activity tracker, app), the D2.2. is a distinct overview of the data that is needed to respond to the ValueCare approach and how the exchange of the needed data between health and social services is supported.

## 6 References

Abdel-Khalek, A. M. (2006). Measuring happiness with a single-item scale. *Social Behavior and Personality: an international journal*, *34*(2), 139-150.

Hoefman, R. J., van Exel, J., & Brouwer, W. B. (2013). Measuring the impact of caregiving on informal carers: a construct validation study of the CarerQol instrument. *Health and quality of life outcomes*, *11*(1), 1-13.

Hughes, M. E., Waite, L. J., Hawkley, L. C., & Cacioppo, J. T. (2004). A short scale for measuring loneliness in large surveys: Results from two population-based studies. *Research on aging*, *26*(6), 655-672.

Lee, P. H., Macfarlane, D. J., Lam, T. H., & Stewart, S. M. (2011). Validity of the international physical activity questionnaire short form (IPAQ-SF): A systematic review. *International Journal of Behavioral Nutrition and Physical Activity*, *8*(1), 1-11.

Miller, W. R., & Rose, G. S. (2009). Toward a theory of motivational interviewing. *American psychologist*, *64*(6), 527.

Romero-Ortuno, R., Walsh, C. D., Lawlor, B. A., & Kenny, R. A. (2010). A frailty instrument for primary care: findings from the Survey of Health, Ageing and Retirement in Europe (SHARE). *BMC geriatrics*, *10*(1), 1-12.

Sangha, O., Stucki, G., Liang, M. H., Fossel, A. H., & Katz, J. N. (2003). The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Care & Research: Official Journal of the American College of Rheumatology*, *49*(2), 156-163.

Scheffer, A. C., Schuurmans, M. J., Van Dijk, N., Van Der Hooft, T., & De Rooij, S. E. (2010). Reliability and validity of the visual analogue scale for fear of falling in older persons. *Journal of the American Geriatrics Society*, *58*(11), 2228-2230.

Wijnhoven, H. A., Elstgeest, L. E., de Vet, H. C., Nicolaou, M., Snijder, M. B., & Visser, M. (2018). Development and validation of a short food questionnaire to screen for low protein intake in community-dwelling older adults: The Protein Screener 55+(Pro55+). *PLoS One*, *13*(5), e0196406.

Yardley L, Beyer N, Hauer K, Kempen G, Piot-Ziegler C, Todd C. Development and initial validation of the falls efficacy scale-international (FES-I). *Age Ageing.* 2005;34(6):614–9.