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D.2.6 Report on the co-design activities for the ValueCare concept - Protocol to develop the co-design activities at pilot sites

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Abstract

This deliverable presents the guidelines to develop the co-design activities (national seminars, focus groups and world cafes) according to the target groups to be involved in pilot sites (end users - older people and families, health and social care practitioners and managers. The co-design is addressed to jointly develop a new outcome-based social and health integrated care model supported by a digital solution that promotes older citizens health and social goals, supports informal caregivers, and improves professionals' working conditions. End-users' interests are the driving force behind the development process, and the end-users will be involved from the initiation of the research: to define the problems to be tackled, to formulate design criteria and recommendations, and to help find solutions. In this process, the co-design is analysed through the DART model and linked with the engagement strategies developed in the D.2.3. In summary, the guidelines provided in this document are presented as a tool to support pilot sites, but each pilot site should select the actions that best respond to their context and target group.

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EXECUTIVE SUMMARY

This deliverable **2.6 Report on co-design activities for the ValueCare concept** comprises the guidelines to implement the co-design activities in pilot sites. It is addressed to provide pilot sites the tools to implement the co-design activities for each of the ValueCare target groups, although each pilot site should decide the activity to be implemented to gather the information from each target group. Thus, this report defines how to organise different co-design activities, the questions to be discussed with each target, and a series of supporting documents (checklists and reporting sheets). It is important to mention, that the co-design activities proposed in the DoW (national seminars, focus groups and world cafes) had been complemented with other activities to approach the different target groups online and supportive technologies, in order to not delay the project progress due to COVID-19.

It is important also to remark that this deliverable is focused on co-design activities and how to involve ValueCare target groups in this process. For the engagement strategies and the definition of target groups, pilot sites should consult the **deliverable 2.3 on Engagement strategy for the ValueCare concept co-design**. The use of the terms 'user engagement' and 'user involvement', and their application both to individual care and to the planning and design of services can potentially be confusing. The following descriptions will be used for the purposes of this report only to aid clarity and understanding.

Patient/ user engagement: used to describe a users' engagement in either their own health, social care and support services as a recipient or deliverer, e.g. nurse, doctor, social worker, administrator etc.

Patient/ user involvement: used to describe when patients and users (both as individuals and groups) are involved in the design, planning and delivery of health, social care and support services at any level of delivery.

The figure 1 presents a brief overview of the deliverable to guide pilot sites in their reading:
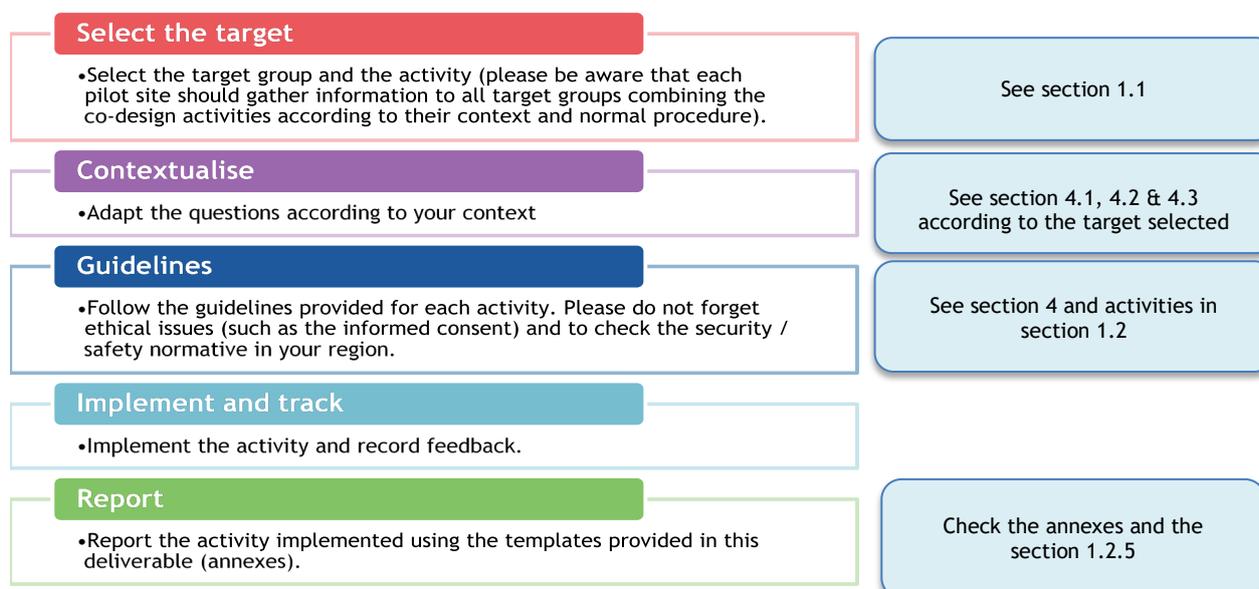

Figure 1. Deliverable overview

Relation to other WPs and deliverables:

This deliverable is strongly linked with the following WPs and deliverables (Table 1):

WP	Deliverable	Link
WP2	D.2.1. ValueCare concept	The co-design activities described in this report and reported in the next versions of this deliverable will feed the ValueCare concept.
WP2	D.2.3, D.2.4 and D.2.5 Engagement strategy for the ValueCare concept co-design start-term/mid-term/end-term	The D.2.6 is strongly linked with these three deliverables, as these three deliverables describe how to engage participants in the co-design activities according to their profile.
WP3	All WP3 deliverables	The co-design activities described in this report and reported in the next versions of this deliverable will feed the ValueCare digital solution.
WP4	D.4.2. ValueCare implementation plan for each pilot site D.4.3. report regarding the implementation of ValueCare in 7 European pilot sites	The co-design activities described in this report should be implemented at least two times along the project execution. Activities performed in the implementation phase can be aligned with the co-design activities.
WP6	D.6.2. Dissemination and communication plan	The ValueCare Dissemination plan can be used to recruit participants for the co-design activities presented in this report.
WP8	D.8.1, D.8.2, and D.8.3 ValueCare ethical management plan	All the activities involving participants should check the ethical guidelines and templates provided in the WP8.

Table 1. Link with other WPs and deliverables

1. From co-creation to co-design

The better way to understand the concept of **co-design** is by framing it within the concept of **co-creation (Figure 1)**. In fact, the practice of collective creativity in design is not new, going under the name of "participatory design", or also more recently, "co-creation" or "co-design". Nevertheless, according to Sanders and Stappers (2008), these two terms are often confused or wrongly treated as synonymous. To the authors, co-creation consists of any act of collective creativity that is shared by two or more people. In this sense, it is a very broad term with applications ranging from the material to the metaphysical. In turn, co-design is seen as the collective creativity applied across a design process, thus appearing as a specific instance of co-creation. For some people, co-design refers to the collective creativity of collaborating designers, although, in a broader sense, it also includes the creativity of people from other professional areas, working together in a specific design development process (Cooper at el., 2013).

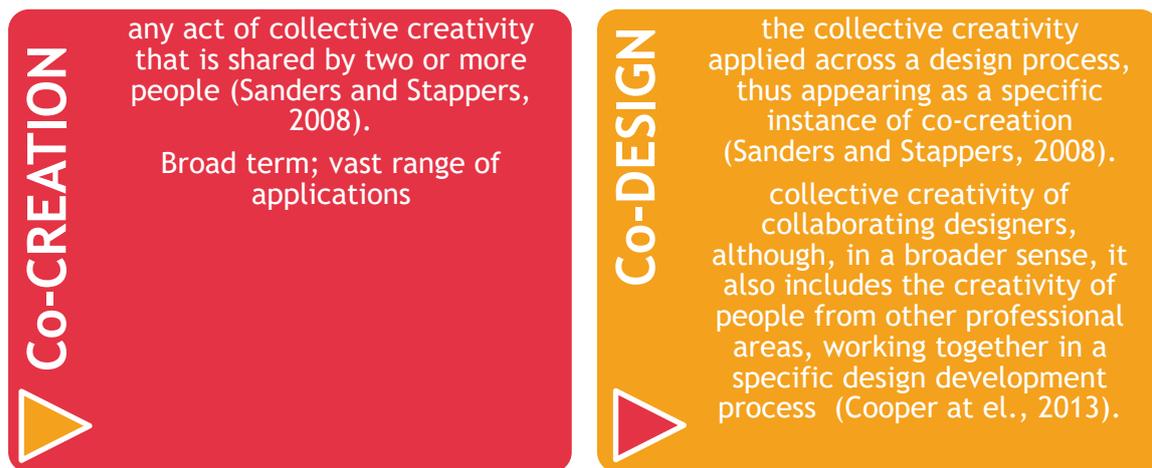| Co-CREATION	Co-DESIGN
any act of collective creativity that is shared by two or more people (Sanders and Stappers, 2008). Broad term; vast range of applications	the collective creativity applied across a design process, thus appearing as a specific instance of co-creation (Sanders and Stappers, 2008). collective creativity of collaborating designers, although, in a broader sense, it also includes the creativity of people from other professional areas, working together in a specific design development process (Cooper at el., 2013).

Figure 2. Co-creation and co-design

Co-design enables a wide range of people to bring creative contribution into a dialogue. It helps participants to formulate a problem and identify possible solutions and/or improvements to existing solutions, mainly at local context. The co-design approach brings participants the opportunity to identify **common challenges and values and discuss how best to address them**. The role of the participants is therefore crucial as the outcomes of the co-design discussion will address the challenge(s) identified by the participants themselves. It is of utmost importance that participants play an active role when taking part in co-design activities, which relies on an equal collaboration between them.

The co-design approach involves different groups of **stakeholders**, including professionals and citizens. While professionals (providers/supply-side) bring their expertise to the discussion and citizens (end-users/demand-side) bring their empirical knowledge, becoming central to the discussion and to the development of solutions (Steen et al., 2011). In the case of **older people**, main target of ValueCare project, this approach brings the ability to better understand older people's daily lives, experience, and abilities (Hofmeester and De Charon, 1999).

If well structured, the co-design approach generates several **benefits** that other approaches (such as the traditional user-centred design) might not lead to:

► The active participation of end-users in co-design activities ensures local ownership of the solutions developed;
► By involving different stakeholders from the same local context in the co-design process, the solutions developed are more likely to address all stakeholders' needs, favouring a holistic approach (Dawda PKA, 2017); and
► By being co-designed, the developed solutions are more likely to be acceptable to both providers and users, and therefore adopted and sustained (Sanders, 2018).

However, it is important to mention also the **risks** related to co-design activities. Among others, as a participatory activity, its implementation might be more unpredictable and might take more time; the dialogue among participants at the beginning could be limited or might need more time for the roll out– especially now with the Covid19 sanitary crisis; participants might fail in articulating clearly the benefits they aim to achieve; and the collaboration might be scarce. In order to **prevent possible drawbacks** to happen, the following factors can be considered when developing co-designing solutions (Progressive):

1   Idea support: The creation of a constructive and positive work environment in which end-users feel comfortable influencing the co-production process.
2   Communication: Giving stakeholders the space to speak and supporting open and frank exchange impacts positively the development of new ideas and enhances participants' dialogue.

3   Collaboration encouragement: Building mutual respect among participants will enhance co-design and will ensure the active engagement of every member involved.

4   Awareness of potential conflict: potential conflicts which may arise during the activity will benefit the participants' creativity and will foster debate.

5   Tolerance of failure: Being aware that co-design brings uncertainty and risks will help to learn from possible mistakes and start again by taking into consideration the experienced issues.

6   Goals and benefits: a mismatch between the benefits of co-design and the project goals could appear. The people involved in organising co-design activities should first identify the specific goals of the project as well as the possible benefits of one or more co-design activities, and then align these goals and these benefits (Steen et al., 2011).

Irrespective of the methodology chosen, pilot sites' coordinators should consider some **essential points** of departure before implementing a co-creation activity, namely (Fontys, 2018):

1   the aim of the co-design activity;
2   the actors to be engaged;
3   the needs to be addressed;
4   relevant factors, such as social, environmental (accessibility), local factors and the health condition of the participants which might influence the co-design activity and the interaction between participants; and
5   the frequency the co-design activities will need to be carried out.

These questions might be useful to collect as much information as possible before the implementation of the co-design activity and to start thinking about opportunities, challenges and needs which need to be addressed.

In sum, in order to achieve positive results in a co-design process, participants should lead the co-design activity, but with the help of the **coordinator**. In this sense, the guidelines presented in this document are designed to be followed by **ValueCare pilot sites coordinators** when they organise the activities that will be performed in each pilot site. The coordinator can implement them alone or with the support of **moderators, community leaders, etc**.

1.1. Deliverable objectives and scope

The **main objective** of this report is to provide the 7 pilot sites of the ValueCare project the tools to implement the co-design activities for each of the ValueCare target groups. On this basis, the following **specific objectives** are addressed:

- To involve the end-user in the ValueCare project.
- To define how to organise different co-design activities.
- To define alternative co-design activities to be performed online.
- To suggest activities to be included in the agenda of the co-design sessions.
- To provide pilot sites the questions to be discussed with each ValueCare target group.
- To provide pilots a series of supporting documents (checklists and reporting sheets) to implement and report the co-design activities.
- To link the co-design sessions with the engagement strategy developed in the deliverable 2.3.
- To facilitate the feedback to be provided to the definition of the ValueCare concept and digital solution.
- To foster the dialogue between the different ValueCare target groups (in the new versions of the deliverable).

1.2. Target groups

For the co-design activities, the 7 pilot sites should involve the end-users (older people and families, health and social care practitioners, and managers) and the stakeholders using the most appropriate co-design activity according to the target group profile, as summarised in the following table (Table 2):

Pilot	Target		Stakeholders
	End-users		
Rijeka (Croatia)	Older citizens that had a heart attack and finished their rehabilitation	Families Practitioners (GPs, social care-community professional – geriatrics, nurses, educators and health workers in general) IT technicians	Volunteers, community nurses, NGOs, Clinic for rehabilitation
Athens (Greece)	Frail older people with neurological problems		AMC and AFIC, informal caregivers
Cork/Kerry (Ireland)	Older people (>75) with mild to moderate frailty)		Care coordinator Caregivers
Treviso (Italy)	Older people +65 with a MCI diagnosis		Regional health authorities, policy makers, municipalities social services, and caregivers
Coimbra (Portugal)	No or mild cognitive impairment, with comorbidities[1] and lack of social and family support		Caregivers
Valencia (Spain)	Frail older people		NGOs, informal caregivers, health department VLC-Clínico-Malvarrosa
Rotterdam (the Netherlands)	Stroke patients		academic hospital (EMC), health insurer, rehabilitation clinic, nursing home, a primary care organisation of GPs, the local municipality, data handling company, personal health record company, a provider of innovative physical therapy, and a foundation supporting healthy lifestyles.

Table 2. Target groups per pilot site

To facilitate the work to pilot sites, **three main target groups** had been identified (assembling those detailed in the table above) to be engaged and involved in the ValueCare co-design activities:

1 Older people and their families: 20 older people and 20 informal caregivers.
2 Health and social practitioners: 10-15 professionals.
3 Health and social care managers with decisions in health and social systems (integrated care): 5 health and social care mangers also considering ICT managers

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[1] Still to be confirmed

(Chief of the ICT departments of local stakeholders such as Health or Social services, Municipalities).

A complete description of these three target groups is included in the **D.2.3 on Engagement strategy for the ValueCare concept co-design**.

1.2. Co-design solutions with end-users in ValueCare project

ValueCare proposes three types of co-design activities: **national seminars, world cafes and focus groups.** These activities were proposed for a particular target group and content (see Table 3), but after internal discussion with project partners, it was agreed that pilot sites can use them for the target group and content they consider according to their normal procedure. At the end, all pilot sites should gather the relevant content and involve all the target groups, as described in the next section, but the process to collect the information and involve them can be adapted to the normal procedure and context of each site:

Co-design activity	Target group	Content to gather
National seminars	Wide public	Initial suggestions on how the ValueCare concept should be and how the supportive IT solution should be integrated to respond to the needs of the target groups.
World Café	End-users (older people, families, health and social professionals, and managers)	Feedback to the ValueCare approach presented (ValueCare concept and IT solution)
Focus groups	Experts in the field (health and social field, and IT) and policy makers	ValueCare standards, approach, and interoperability

Table 3. ValueCare proposal for co-design activities

In addition to previous activities, a **video to socialise the ValueCare project** is also developed by partners to start with the co-design activities in the COVID-19 period. In this sense, pilot sites also suggested to start with some online activities during the COVID-19 period as **interviews and using social networks**. Along the next sections, these co-design activities proposed by ValueCare partners are also described in detail.

Informed Consent form for older people[2]

Considering the informed and voluntary participation of older people in the co-design activities for the ValueCare project, as well as the safeguarding of their own rights and interests, each pilot will be provided with a common template for the Informed Consent procedure[3] (composed by a triple pack), leaving the possibility open for them to adapt it according to their specific local demands.

This document, to be distributed and signed by each one of the co-design session participants, whether in focus groups, world cafés or in national seminars, will contain three main sections:

► a first one dedicated to **general information** about the study, detailing aspects related to the logistics about the venue, the purpose and objectives of the project as its co-design activities, the main responsible contacts, the associated risks and benefits for

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[2] NOTE: in case pilot sites do not need to use informed consent to implement the co-design activities, they can omit this step.
[3] NOTE: Considering that an informed consent template is to be provided at M12 (November) by D.8.4. VALUECARE ethical guidelines and templates [led by CDC], under T8.2 Ethical Protocols, in d2.4 it will be provided a draft version of the IC for pilot sites to use within the co-design activities (in September), the final version will be included in D8.4. Also suggestions on how to include it in online activities will be provided.

the participants, the data protection procedures, any reimbursement forms (if it is the case, for example in case of travel expenses) and the individual right of withdrawal;

► a second one consisting of the actual statement of **consent** from the participant; and

► a third one regarding the **revocation/withdrawal form**, to be signed by the participant in his/her own handwriting, in case he/she wishes to interrupt their participation or leave the ValueCare study.

The next sections of the deliverable provide a detailed overview of the different methodologies that pilot sites can apply to co-design solutions with end-users in the ValueCare project.

1.2.1. Co-design activities proposed during COVID-19

Covid-19 is causing huge upheaval, particular to the lives of older people. The success of the ValueCare project relies on finding effective new ways of engaging older people, health and social care practitioners and others in co-design activities. Video conferencing technologies will be used as much as possible to facilitate co-design activities, including focus groups, world café, and target groups. ValueCare website can be used to disseminate and engage participants in the co-design activities. Video conferencing will enable linking with groups of older people that may be in residential homes or sheltered housing complexes so there could be linking to individuals or linking to several groups of individuals as required; also targeting family caregivers who may be likely to use technology to assist older people. This approach is likely to bias activities to those who have access to videoconferencing and will need to be monitored during Covid-19 and managed beyond it, meaning that the stakeholders with no access to internet or videoconference devices will not be able to provide input at this stage of the co-design process. ValueCare partners will have to assess when it will be safe, in terms of sanitary measures, to include these missing stakeholders.

Social networking platforms, such as Facebook, WhatsApp and Twitter, may be considered as *complementary* engagement activities (e.g. carrying out a survey through WhatsApp), however due to the potential access limitations, these are not recommended as a major activity.

In this sense, this report presents **three complementary activities** to be used for co-design during the Covid-19 period: video, interviews, and survey.

Video to socialise the ValueCare project

Description: the video is a support material to contextualise the aims and objectives of the ValueCare project.

Benefits: it allows to raise awareness of ValueCare project, engage older people, their families and the care team in a virtual way given that due to the pandemic face-to-face events are not possible, begin to co-design solutions and keep momentum going.

Weaknesses: Some older people and their families may not have access or be able to engage with the video and any relevant virtual events. Risk of selection bias as those participating will be required to use digital solution for connection.

Preparatory actions: Support older people and their families who do not have their own digital solution/ technology to access it through neighbours and or friends or communities where possible. Post-covid19 pandemic, making special efforts to reach out to people that could not access video and any virtual events. Noting the selection bias so that it can be accounted for in the analysis.

Recruitment:

► Older people and families: getting in touch with stakeholders in the community who would act as intermediaries between the pilot site and the older person and their family.

► Health and social practitioners and managers: sharing the video through all partners networks, requesting the pilot leads to disseminate via their partners and relevant

practitioners' organisations and health care facilities. Considering lists, for example, of medical practitioners in the local area.

Organisation: not relevant

Resources needed: IFIC is currently exploring options for applications to develop the animation video. For pilots and participants, the resources needed are internet access so that the video can be accessed online or access to a device where it has been previously downloaded.

Interviews

Description: targeted, semi-structured interviews with older people, health and care practitioners and managers (the three key stakeholder groups) to help elicit a more in-depth understanding of the requirements to inform the process of co-design.

Benefits: particularly useful at the outset of the project, interviews serve to inspire and inform. They are an effective way of engaging stakeholders and allow more flexibility in terms of exploring any topics that arise and delving into them in more detail. They are a useful way to test ideas quickly and get a sense of general patterns/ themes.

Weaknesses:

- ► The views of interviewees do not necessarily reflect the reality for the wider group of stakeholders. There may be things the interviewee does not remember or thinks relevant to bring up.
- ► Enough interviews need to be carried out to enable the identification of themes/ patterns (i.e. it is easy to spot when you reach 'saturation point' when interviewees responses keep repeating themes that have already been recorded).

Preparatory actions:

- ► Confirm list of best candidates for potential interviews.
- ► Identify trained/ experienced interviewer to carry out the interviews and the analysis.
- ► Agree interview logistics (phone, facetime or videoconference).
- ► Write semi-structured interview guide - not exhaustive lists of questions, but the key points to be covered (remember to allow enough freedom for the subject to open up and discuss wider concerns). Please use the questions proposed in section 4 according to the target group. Those questions can be shared in advance with the interviews.
- ► Prepare invitation to be interviewed with all the relevant information about the project, objective of the interview, noting that responses will be confidential and no information about the interviewee will be shared with anyone.
- ► Thematic analysis of interview responses.

Recruitment: can follow the same as those described in the next section for focus groups.

Organisation:

- ► Prepare the virtual room (phone, facetime, or videoconference); be sure that there is no back noise that may interfere in your communication with the interviewed.
- ► Check if the interviewees have signed a consent form to take part in the activity if foreseen.
- ► Clarify the purpose of the interview and the goals of the meeting, as well as the structure of the interview.
- ► Ask the permission for recording the interview, to better keep track of each intervention.
- ► Start with the questions, give space for answering (work on your listening skills) and be objective.
- ► When all the questions have been asked, the interviewer will give the chance to the interviewee for providing final comments/points.
- ► Thank the participation and explain next steps (share the results, potential more interviews…).

Resources needed: interviewer, phone, or videoconferencing facilities.

Online survey

Description:

Benefits: An online survey can be rapidly deployed and completed by participants, particularly when disseminated via social media and/or email, or where an incentive is offered for completion. There are minimal costs involved as delivery of the survey questions and capture of the responses is automated, reducing the need for paid researchers to ask face-to-face questions or enter data, reducing also data entry errors (Callegaro et al., 2015). The lack of an interviewer also reduces social desirability bias (the tendency of respondents to provide answers that they assume the interviewer will expect to hear) (Phillips & Clancy, 1972) and ensures that each respondent receives the survey questions in exactly the same way (Bernard, 2011).

Moreover, it is often preferred by respondents, who can answer at their convenience and at their own pace, which may increase response rates (Callegaro et al., 2015). Complex questions or questions that involve a long list of response categories can be hard to follow orally but when delivered in a self-administered survey can be presented simply and in more interesting and engaging ways (Bernard, 2011).

Finally, data can be downloaded in a variety of formats and imported into analytical software packages.

Weaknesses:

►   Open-ended question responses cannot be explored with immediate follow-up questions and there is no scope for respondents to seek clarification of unfamiliar or ambiguous terms.
►   Self-administered questionnaires are not useful tools for studying non-literate or illiterate populations, or those who cannot proficiently use technology (Bernard, 2011).
►   The use of virtual internet communities, social media, and email to distribute invitations to participate in a survey may also lead to problems of sample bias (Alessi & Martin, 2010).

Preparatory actions:

1   The first step is to design the questionnaire with the following sections: introduction with the ValueCare concept and aims, details of what the participation will entail, confirmation of ethical approval, and questions. The questions should be based on the questions included in the section 4. Bernard (2011) described 15 well-understood rules that should be followed when constructing survey items which include: be unambiguous; use vocabulary that your respondents understand; pay careful attention to contingencies and filter questions; offer respondents a "don't know" option; and avoid loaded and double-barrelled questions.
2   Once you have the questionnaire, put it in an online tool (e.g. REDCAP[4]).
3   Then test it with your colleagues to confirm that the questions capture the information you wish, are understandable, do not required so much time…

Recruitment: can follow the same as those described in the section for the video.

Organisation: distribution, publicity and then data collection and analysis.

Resources needed: online questionnaire (google, survey monkey, etc.)

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[4] https://www.project-redcap.org/

1.2.2. ValueCare co-design activities

As mentioned, in the ValueCare DoW, partners included three co-design activities: national seminars, focus groups and World Cafés. These activities are described in detail below.

National seminars

ValueCare proposal included national seminars as one of the co-design activities; although, after discussing among the partnership there is a common concern on the notion of "national"; more than national, the seminars should be quite local given the territorial characteristic of the pilot sites involved. Of course, pilot sites can invite also national actors (e.g. healthcare authorities) to widespread the ValueCare concept and solution and invite them to take part in the co-design process when relevant.

Description: a seminar is a conference or another meeting for discussion or training. In ValueCare it is conceived as an open event to gather information to build the ValueCare concept and solution and also to present project progress and results.

Benefits: with this activity, organisers can put together a big number of participants and speakers connected with ValueCare's aim. It can be designed by sessions also in parallel according to different target groups' interest, allowing also flexibility in sessions participation and duration.

Weaknesses: bringing people together will require resources (time and sometimes budget to cover coffee breaks and renting rooms). A well-defined and attractive agenda should be provided to attract and involve participants and do not loose participation, also in future events.

Preparatory actions:

1. Define your goals in relation to gather information to respond the questions included in section 4.
2. Select a data, venue, and attendee profiles (please adapt the venue to the participants requirements).
3. Define an agenda with, in case, speakers.
4. Disseminate the event
5. Arrange the catering and seminar needs (screens, micros…)
6. Prepare, in case, all event materials, displays, gifts, registration tables, name badges, etc.

Recruitment: pilot sites can use their already existing networks to invite the target groups to participate in the event (social networks, mailing lists, noticeboards…).

Organisation: specific co-design activities with small groups

Resources needed: budget to cover coffee break and room renting, personnel to organise and manage the different seminar's sessions, screens, micros…

Where possible, representatives of the ECHA ecosystems network will be involved. For example, ECHA have an active ecosystem in Ireland that would be happy to participate in the co-creative event. The invitation can be obviously addressed to those actors that are relevant to the project. This will enlarge the stakeholder's basis from the very beginning of the activities and echo other voices in addition to the ones that will be identified in each pilot site.

ValueCare approach: each pilot site can organise dedicated seminars open to wide public to collect the initial suggestions on how the ValueCare concept should be and how the supportive IT solution should be integrated to respond to the needs of the target groups.

World Cafés

Description: The World Café is a method which adopts an informal café setting for a group of people to explore an issue by discussing it in small table groups. Discussion is usually held in multiple rounds of 20-30 minutes, with a café-type ambience created.

Benefits: This method allows for more relaxed and open conversations to take place where participants can talk about things that matter to them.

Weaknesses: The method is based on the assumption that people already have within them the wisdom and creativity to confront even the most difficult challenges and rests on two key principles: (i) humans want to talk together about things that matter to them; and (ii) if they do, they can create collective power. As older people will make up a significant number of participants, it may be that they do not feel comfortable in such discussions or really feel that they can create collective power. It may be necessary to involve family members of people living with cognitive decline.

Preparatory actions: First of all, the coordinator should define the:

▶ Target group addressed: identify the focus group to involve in the World Café.
▶ N° of participants: The whole group size is flexible, but each table should ideally consist of 4 participants (chairs), maximum 5.
▶ Structure: World Cafés are structured around a set of questions, which are usually no more than 10. It needs to be kept in mind that, even if the questions will drive the discussion, space for free-flowing discussion needs to be considered. Participants should be allowed to both contribute their ideas and listen to others as they wish.
▶ Timing: Define an initial timing of the World Café adapted to the target group.
▶ Venue: The venue of the World Café should be a suitable space that supports good conversations. Participants should be able to move between tables, meet new people, actively contribute to the thinking. As participants carry key ideas or themes to new tables, they exchange perspectives, build their thinking and greatly enrich the possibility for new insights to be shared. Moreover, the venue needs to be accessible to everyone; this is especially relevant if you are implementing the World Café with older people with different health conditions.

As a next step, the coordinator will structure the World Café activities around a set of questions which will be agreed by the ValueCare Consortium (and tailored to the target group addressed in this activity). These questions will be asked during the World Café and will trigger the discussion among participants. The coordinator will ask participants a maximum of 10 questions, developed by the consortium, and she/he will make sure that:

▶ The questions are clear, short and focused, so that every participant can understand the meaning. If needed the coordinator should adapt them to the pilot context.
▶ The questions are open-ended (starting with "how", "why", "what"), to stimulate a rich conversation.
▶ The questions are divided into 3 different types: Probe questions (introducing the participants to the topic), exploration questions (getting to the point of the discussion) and exit questions (checking to see if anything was skipped in the discussion).

Recruitment, Organisation and Resources needed: can follow the same as those described in the next section for focus groups. But in the organisation, the coordinator should:

▶ Ensure each table lead is a good listener and the participants are briefed to listen to each other.
▶ "Harvest" the essence of each tables' discussion through a feedback and reflection session towards the end of the event.

More information on the World Cafe format can be found here: http://www.theworldcafe.com/wp-content/uploads/2015/07/Cafe-To-Go-Revised.pdf

ValueCare approach: each pilot site can organise a World Café to foster the discussion about ValueCare concept and IT solution with participants.

Focus Groups[5]

Description: A focus group is a method of qualitative data collection to gain deep insight information. By creating accepting environments, where participants feel comfortable to share their concrete experiences with the rest of the group and to be asked their opinion. Thus, questions and specific points are raised in an interactive group setting and members of the groups are encouraged to speak and to give their view on a selected topic. Normally, focus groups work better with small group (8 people maximum) and should not be longer than 2 hours.

Compared to other methods, such as surveys, focus groups allow understanding things at a much deeper level. By creating a friendly, accessible, and safe space, participants will feel very natural and relaxed to talk with a group of strangers.

Benefits: Focus groups...

- ► ... help to 1) identify a problem; 2) plan how to achieve a set of goals; and 3) understand and assess how a plan/project is moving forward.
- ► ... provide a bottom-up approach. You can provide examples of eHealth technology to prompt discussion and identify user needs. You can also consider a shot attitudinal rating scale in which participants rank their needs.
- ► ... facilitate the interaction among a group of different stakeholders and enable them to share several perspectives and inputs.

Weaknesses: Focus groups...

- ► ... require a lot of planning and their organisation is time-consuming.
- ► .... may face some reluctant participants to share personal information, or they might have difficulties in sharing their experience; also some participants can dominate the focus group and facilitator must intervene without disrupting the rapport in sharing ideas.
- ► ... if required several iterations with the same participants, organisers will need to consider that participants might abandon for several reasons, e.g. health condition, busy work schedule.

Once the coordinator has set up the goals of the focus group; there are different steps to be implemented:

Preparatory actions:

First of all, the coordinator should define the focus group:

- ► Target group addressed: identify the focus group to involve in the focus group.
- ► N° of participants: the group needs to be large enough to generate rich discussion; but too many participants may prevent people from participating in the discussion. It is recommended to have an average of 8 participants.
- ► Structure: Focus groups are structured around a set of questions, which are usually no more than 10. It needs to be kept in mind that, even if the questions will drive the

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[5] Please consider that focus groups can also be organised online using teleconference tools given that the participants are previously trained or area acquainted with the digital tool.

discussion, space for free-flowing discussion needs to be considered. At the beginning, you can use an icebreaker or spend time for a general question/chat to develop rapport between the facilitator and participants, as well as between participants.

► More than one session: to produce valid results, more focus groups are needed (usually 3 or 4). When the group will not have anything to say anymore, it means that enough sessions have been run and that the set of goals has been achieved.
► Timing: Define an initial timing of the focus group adapted to the target group.
► Venue: The venue of the focus group needs to be selected carefully. This is especially relevant if you are implementing the focus group with older people with different health conditions. The venue needs to be accessible to everyone.

As a next step, the coordinator will structure the focus groups' activities around a set of questions which will be agreed by the ValueCare Consortium (and tailored to the target group addressed in this activity). These questions will be asked during the focus groups and will trigger the discussion among participants. The coordinator will ask participants a maximum of 10 questions, developed by the consortium, and she/he will make sure that:

► The questions are clear, short, and focused, so that every participant can understand the meaning. If needed the coordinator should adapt them to the pilot context.
► The questions are open-ended (starting with "how", "why", "what"), to stimulate a rich conversation.
► The questions are divided into 3 different types: Probe questions (introducing the participants to the topic), exploration questions (getting to the point of the discussion) and exit questions (checking to see if anything was skipped in the discussion).

Recruitment:

Older people and families:

Older people might be difficult to access. However, it is essential to have a representative sample to gather standardised data. They can be recruited by (Kammerer et al., 2019):

► getting in touch with stakeholders in the community who would act as intermediaries between the pilot site and the older person and their family
► recruiting randomly from a sample from the population registry of the city through a letter of invitation
► Accepting volunteers who may come forward once the relevant information about the pilot site's activities have circulated.

Health and social practitioners and Health and social managers:

When recruiting these target groups, we should take into account the different positions that several practitioners might have and the different ways they interact with end-users during their work. Therefore, we should consider the heterogeneity of the groups; and make sure our sample is representative of all (or most) of them. They can be recruited by (MacDougall, 2001):

► Considering informal networks of colleagues which may be linked to some person working in the pilot's site
► Contacting existing practitioners' organizations, as well as health care facilities
► Considering lists, for example, of medical practitioners in the local area
► Sending individual letters followed by a phone call to confirm the participation and stressing the relevance of having that person (e.g. health or social manager) on board.

In general, it should be considered that:

► All the participants should be very comfortable with each other but none of them should know each other.
► The group should be balanced. Therefore, it is important to check participants' sex, age, educational level.

Organisation:

► Prepare the room where the focus group will take place, be sure participants will feel comfortable, there is enough light and water for participants. Also check you have all the materials you need (pens, paper…).

► As a first step, it is essential to check if all the participants have signed a consent form to take part in the activity (included in the information package).

► When the group come together, it is important to clarify the purpose of the focus group and the goals of the meeting, as well as the structure of the session. The coordinator or moderator should clarify how they will proceed and how each member can contribute.

► Before starting the discussion, it might be helpful to ask the permission to the participants to record the session, in order to better keep track of each interventions.

► The moderator can start asking a first general question. For each question asked, space will be given for an open discussion, followed by a wrap-up by the moderator.

► When all the questions have been asked, and before the group ends, the moderator will give the chance to participants for providing final comments/points to be further discussed.

► The moderator will tell the members about any next steps that will occur, and what they can expect to happen.

Resources needed:

► Time

► Safe and accessible space when participant can feel comfortable to share their experience

► A moderator/coordinator inspiring the discussion and a note taker. The moderator should be a neutral person, not necessarily connected to the aspects discussed.

► Tape recorder record the session

► Materials needed if you plan to do the activity more participative (pens, markers, notebooks, flip chart...)

ValueCare approach: partners can organise focus groups with 8-10 participants to discuss about the ValueCare approach.

1.2.3 Optional activities to include in the agenda

Pilot sites can enrich the activities detailed before with some engaging activities, such as:

► **Needs Assessment Exercise** This visual tool draws out information about people's needs, raises participants' awareness of related issues and provides a framework for prioritising needs.

► **SWOT analysis** (Strengths, Weaknesses, Opportunities and Threats) is a method of systematic group reflection addressed to gather, analyse and evaluate information and identify strategic options facing a community, organisation or individual. It is often portrayed as a 2x2 matrix, which presents an overview of major issues to be considered in developing strategic plans for an organisation – and in preparing Foresight studies in expert panels and workshops. Thus, it categorises significant internal and external factors influencing an organisation's strategies/model – or, in the case of Foresight, its possible futures. It generally provides a list of strengths and weaknesses based on an analysis of an organisation/model resources and capabilities, plus a list of the threats and opportunities that an analysis of its environment identifies.

► **Tree Diagrams** are multi-purpose, visual tools for narrowing and prioritising problems, objectives, or decisions. Information is organised into a tree-like diagram. The main issue is represented by the tree's trunk and the relevant factors, influences and outcomes will show up as systems of roots and branches. As a community participation exercise, tree diagrams can help people to uncover and analyse the underlying causes of a problem or to rank and measure objectives.

► **Scenarios** (Asselt et al, 2001; Krueger at al., 2001) are visions of future states and paths of development, organised in a systematic way. They can be either extrapolative or normative but should enable participants to build internally consistent pictures of future

possibilities and are useful for envisaging the implications of uncertain developments and examining the scope for action. Scenario analysis engages a group in a process of identifying key issues and then creating and exploring scenarios in order to explore the range of available choices involved in preparing for the future, test how well such choices would succeed in various possible futures and prepare a rough timetable for future events.

► **Patient journey** (Simonse, 2011) is a comprehensible representation of a health service and its procedures, including relationships and feelings from a patient perspective. The different actors that the patient meets during his/her journey are part of the patient journey and their interaction is described in the service touchpoints. Redesigning these touchpoints can play a key role in improving the selected healthcare service. To date, less framing and in-depth understanding on the emerging phenomenon of patient journeys exist.

► **Interactive Backcasting** (Simonse, 2011; Kerkhof, 2002) is an exercise in which stakeholders choose one or several future images as the starting point for their analysis and subsequently (ideal value based health approach), in working backwards to the present situation, interactively explore which interventions are needed to realise this future. In this exploration, the stakeholders identify milestones to be passed, opportunities to be taken and obstacles to be overcome 'along the way'. The method not only shapes the diversity between the future and the present but also between the many views and perceptions of the participants.

1.2.4 Some general tips:

► Keep a simple meeting agenda
► Adapt and translate the ValueCare questions to make them easy to understand to your target group
► Use a common terminology to make sure every participant can understand what you are saying
► Make sure to have a balanced group of participants (e.g. gender)
► Give time for open discussion
► Consider any expenses of the participants (reimbursement form)
► Follow-up participants with the results of the session
► For older people -> Keep in mind accessibility issues that older people might experience when participating into previous activities (e.g. movement, hearing and vision impairments)
► Check the safety/security normative in your local context

1.2.5 After the co-design activities:

► Coordinators will fill in the template that collects all relevant information shared during the co-design activity (ANNEX).
► Look closely at the information collected.
► Share the results with the group with a brief report with the main conclusions (by mail, phone, physically).
► Monitor the data collected during the co-design activities.
► Assess what part still needs to be investigated with the end-users and study the need to conduct a new co-design activity with the target group.

2. The DART model

The DART Model was originally developed by Prahalad and Ramaswamy (2004) to build interactions between the firm and consumers to facilitate the co-creation experiences[6], in a broader sense. In this model, four elements are combined to achieve an effective co-creation process: **DIALOG** is an important element in the co-creation process that implies interactivity, deep engagement, and the ability and willingness to act on both sides. According to Prahalad and Ramaswamy (2004) it is difficult to envisage a dialog between two unequal partners. So, for an active dialog and the development of a shared solution, both sides must become equal and joint problem solvers. But the dialog is difficult if participants do not have the same **ACCESS** and **TRANSPARENCY** to information. The three together (dialog, access, and transparency) can lead to a clear **ASSESSMENT** of the risk-benefits of a course of action and decision.

Example from Prahalad and Ramaswamy (2004):

Should I change my medication? What are the risks? Instead of just depending on the doctor—the expert—the patient has the tools and the support structure to help make that decision—not in some generic risk category but "for me"—with a medical condition, a lifestyle, or social obligations. This is a personalized understanding of risk-benefits.
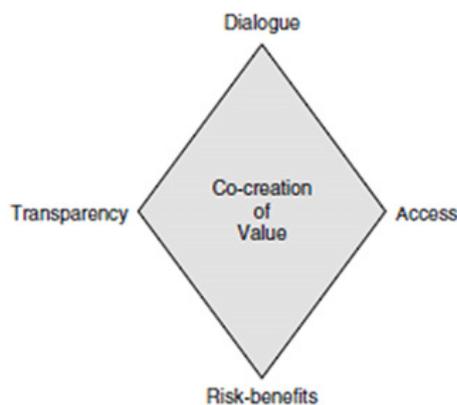
Nevertheless, applying the DART model to ValueCare scope and purposes implicates to perform 2 main adaptations: one regards its implementation to the field of healthcare instead of business, and the other one concerns the replacement of the broader term "co-creation" by the term "co-design", as better explained through 2.1 and 2.2 sections.

Figure 3. DART model

2.2. DART model in health and social care

The DART model is widely used in the commercial field because it supports firms to define and classify value co-creation behaviour (Prahalad and Ramaswamy, 2004). However, in ValueCare this model is used to explore the co-creation of value between the target groups already identified in health and social care. In fact, the effectiveness and quality of health and social care and concrete treatments can be improved by joining efforts between health and social care practitioners and patients. For that reason, it is important to move from a patient centred approach to introduce value co-creation theory in the health field. Indeed, previous studies evidenced the relevance of value co-creation in the medical field reported by patients (Mai and Wang, 2019), and informal caregivers (Sorrentino et al., 2017).

2.2. DART model in ValueCare co-design

Applying the DART model into ValueCare implies to follow the four basic DART components involving the three target groups (older people/families, health and social care practitioners, and managers) to co-create the ValueCare concept, as also its deriving IT solution. However, and considering the original DART model concept of "co-creation", it also requires to strengthen

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[6]   As described above, co-creation is a broad concept in which co-design is included. In this sense, at this stage of ValueCare, the activities are addressed to co-design the ValueCare concept and solution and, once the app and concept is designed, to co-create them.

it into the concept of "co-design" (a narrower term inside the first one, as better explained in chapter 1), in order to make it more suitable, considering the predicted process of collective creativity and design along with primary, secondary and tertiary end-users, not only around the ValueCare model and concept, but also around the functional and the technical features of the ValueCare digital tool to be launched. **Thus, at this stage of ValueCare project, the co-design activities will be addressed to define the concept of value, under the different target groups perspective on health and social care, and the treatment pathways where ValueCare can bring benefits. The interaction between the described target groups is foreseen for later stages of the ValueCare project, so this section will be enriched in the next deliverable versions.** Anyway, a brief overview of the implications of the DART model in ValueCare are described below:

1. Dialogue between older people/families, health/social care practitioners and managers

The literature emphasises that "the understanding of caregivers' needs, their varied experiences and the complex interactions between caregivers, healthcare professionals and patients is important if effective care is provided (Docherty, 2008). In this view, the ValueCare solution ultimately intends to deliver a digital platform and app able to improve the communication between the main stakeholders involved in a specific patient's care pathway, making it more efficient, useful and updated, and therefore facilitating health and social care provision and reception.

2. Access to data for older people and families

Patients and families can nowadays use several devices to access and upload health data directly (sensors, telecare, telehealth, telemedicine, etc.). Data can be consulted with different purposes: collecting and analysing, monitoring, and alerting, diagnosis and treatment at distances, or communication (Gentles et al., 2010).

However, either the design of the ValueCare solution, as the latest pilots implementation will have to comply with the current European GDPR regulation, in order to ensure that all ethical, security and data protection issues are satisfactorily approached and dealt with. This will include respecting the primary end user wishes and options regarding the share of their own personal health or social data with a formal or informal carer. The older adults' privacy and control over their information must not ever be neglected. This means that the user should be able to select which data he/she wants to share and with whom.

Taking these issues into account, also within the ValueCare co-design sessions, will not only feed the patient empowerment, but also probably enrich the concept of value, under health and social integrated care scope.

3. Risk mitigation

The risk mitigation in ValueCare will be directly linked with the impact expected in each of the target groups addressed. As described below, this is part of the evaluation phase of the project implementation (WP5):

Older people: ValueCare aims to improve the quality of life of older people providing them the required and valuable care they need. For that reason, the benefits on this target will be measured through:

- ► ICHOM standard set for older person
- ► Health and Quality of Life: EQ-5D

Families: in the same line of older people, ValueCare also aims to increase the quality of life of families (informal caregivers). To measure this, partners will assess:

- ► The burden of care: Carer's financial burden (Productivity Cost Questionnaire - PCQ) and Zarit Caregiver Burden
- ► The quality of life: Health-related quality of life (HRQoL)

Health and social care practitioners: ValueCare will monitor and support the improvement in working conditions and wellbeing of professionals. Pilot sites will use:

- ► the Culture of Care Barometer tool (Rafferty et al., 2017) designed to help organisations to take action to improve working conditions
- ► Professionals' wellbeing will be measured using the Minnesota Satisfaction Questionnaire (Wess et al., 1967) for job satisfaction
- ► the Copenhagen Burnout Inventory (Kristensen et al, 2005) for burnout
- ► Health: Health-related quality of life (HRQoL)

Managers: in this sense, ValueCare will evaluate the efficiency gains in terms of resource utilisation and coordination of socio-health care. For that, partners will use Social Return on Investment (SROI) to evaluate the financial and social and health outcomes from quantitative and qualitative perspectives and MAFEIP methodology. Some of the variables are listed below:

- ► Budget impact of the current situation (control group) compared to the situation where ValueCare is applied (intervention group)
- ► Incremental quality of life years: Health outcomes difference - Quality-adjusted life year (QALYs)
- ► Indirect care costs: Carer's financial burden (Productivity Cost Questionnaire - PCQ)
- ► Self-designed items (use of ambulatory, quality of care provisions, etc.)

4. Transparency

The care-work and responsibilities from professionals (Milligan et al., 2011) and the trust on data security and privacy (Van Durme, 2014), impact on the data quality governance and proliferation. In ValueCare, there is a concrete WP on ethics and data protection (WP8) to ensure the participants' data privacy and security, operationalised through a set of deliverables responding to the related demands

In summary, the DART model will be applied as described in table 4:

	Older people	**Families** (Sorrentino et al., 2018)	**Health/social** care practitioners	**Managers**
D	Shared goals and knowledge	Shared goals and knowledge	Time for establishing the common goals	Time for establishing the common goals
A	Technological data access	Technological data access	Time to consult data and analyse them to personalise the older person care pathway	Time to consult data and analyse them to improve the quality of the care provided and optimise the use of resources. Interaction between social and health departments
R	Patient empowerment	Families preparedness	Long-term benefit related to the better care provided	Long-term benefit related to the care provided and the optimisation of resources
T	Engagement (to provide also their data)	Assistance	Time	Legal requirements Time

Table 4. DART Model in VALUECARE

3.   Methodology

This section describes the methodology followed to develop the guidelines for implementing co-design activities in the 7 ValueCare pilot sites. As there is a great amount of validated co-design activities published by recognised entities, partners agreed on not developing new guidelines, but to deliver a supporting document that compiles a pool of existing resources that

can be used by pilots according to their characteristics (context and target groups). In this sense, a **systematic review** has been performed to identify best practices in health and social care service co-design and, then, define the guidelines for pilot sites. The Figure 3 identifies the methodological phases addressed to deliver this document:
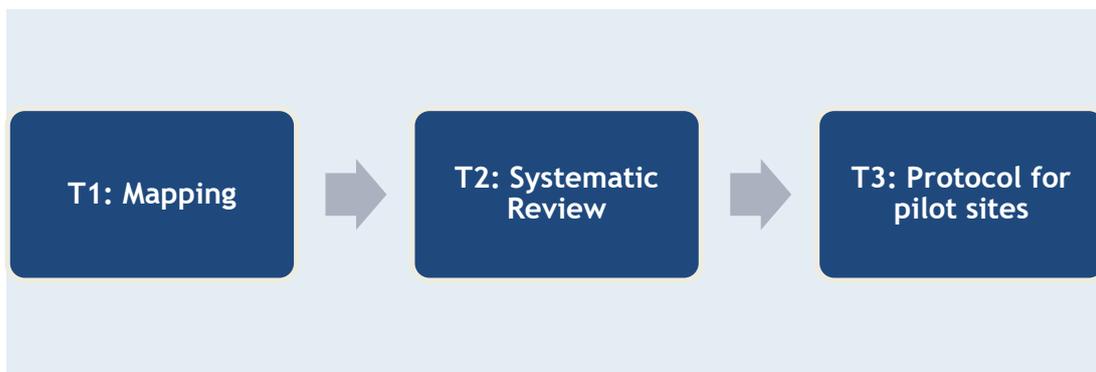
Figure 4. Methodology phases

Task 1: Mapping

The first task was addressed to map existing guidelines that had been used with the ValueCare target groups. After internal meetings with WP2 partners, 3 main target groups had been identified to address the co-design activities (as described in section 1.1):

1. Older people and their families
2. Health and social professionals
3. Managers or policy makers with decisions in health and social systems (integrated care)

KVC, ECHA, IFIC, CDC and AGE collaborated in the mapping activity searching existing co-design activities and uploading them in the shared repository for the project. The relevant information of each report was summarised in a table with the following domains:

► Name of the document
► Target group
► Sample
► Recruitment process
► Topic addressed in the codesign
► Country

From the mapping exercise, 7 methodologies were found, as detailed in the following table 5:

Target group	Guidelines		
Older people and their families	Health service co-design	EBCD: Experience-based co-design toolkit Motivational Model Benefits	SoCaTel[7] co creating for a better life Mobile Age Project inDemand co-creation and business support CoSIE Co-creation Health and social professionals (special chapter for
Health and social professionals			

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[7] NOTE: partners are exploring to use the SoCaTel to be used along the ValueCare project.

Managers or policy makers with decisions in health and social systems (integrated care)			patients with mental problems)

Table 5. Co-design methodologies derived from the mapping exercise

Task 2: Systematic review

The second task was focused to perform the systematic review to identify best practices in health and social care service co-design for digital solutions. For the systematic review the following steps were followed: (i) Definition of the Key words and their relations; (ii) Search in databases; (iii) Definition of the selection criteria; and (iv) extraction of conclusions about how to perform co-design activities with the ValueCare target groups (what kind of activities fit better to each target group, characteristics, organisation…) as well as evidence about what those target groups have already reported to the co-design activities of digital health solutions.

3.2.1. Definition of the Key words and their relations

KVC proposed a set of key words that were presented in the ValueCare meeting in May and discussed with ECHA, IFIC, CDC and AGE. The final set of key words used in the systematic review are (Table 6):

Field	Co-design /Co-creation term	Target group
Health (care)	Co-design Co-creation Contribution	Patient(s) Health & social professionals Health & social managers Families Policy makers
Health and care		
Social (care)		
Care services / care pathways value in care		
Digital health solutions		
	Working with	
Healthcare services	Involving	
Health care services	Accessibility	
Value in care	Expectation	
Sustainability of health- care services	Mutual understanding	
Value in care	Empowerment	

Table 6. Keywords

3.2.2. Search in databases

One open database was selected because their relevance in the health research (**PubMed**). It comprises more than 30 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full-text content from PubMed Central and publisher web sites.

3.2.3. Selection criteria

Together with the selected keywords and the database to be used, partners agreed to limit the search to:

▶ The last three years in order to have the more updated evidence on co-design activities with the three target groups;

► Report written in English language; and
► Papers with the selected Keywords in the title or abstract.

The first search provided a total of 682 papers as detailed in the next table (Table 7):

Key words	PubMed				
	Patient(s)	Professionals	Managers	Families	Policy makers
Health care co-design	91	26	5	25	7
Health care services co-design	1	0	0	0	0
Health care pathways co-design	3	0	0	0	0
Health care co-creation	44	8	0	4	4
Health care services co-creation	16	3	0	2	0
Health and care co-design	112	28	4	30	8
Health and care services co-design	1	0	0	0	0
Health and care pathways co-design	8	0	0	2	0
Health and care co-creation	51	10	0	8	5
Health and care services co-creation	0	0	0	0	0
Health and care pathways co-creation	1	0	0	0	0
Social care co-design	31	14	0	15	0
Social care services co-design	1	0	0	0	0
Social care pathways co-design	2	0	0	0	0
Social care co-creation	12	5	0	3	0
Social care services co-creation	0	0	0	0	0
Social care pathways co-creation	1	0	0	0	0
Co-design value in care	0	1	0	1	0
Co-creation value in care	0	0	0	0	0
Digital health solutions co-design	2	1	0	0	0
Digital health solutions co-creation	1	0	0	0	0
Working with	2	0	0	1	0
Involving (X) in healthcare	0	0	0	0	0
Involving (X) in social care	42	15	1	24	0

(X) is the target group in columns.

Table 7. Search results overview

Previous papers and publications were reviewed and only those that meet the selection criteria were analysed. The agreed selection criteria were:

► Report written in English language
► Covers one of the 3 target groups defined
► Used to create/design a digital health solution/concept
► Published in the last 3 years
► Provided steps for implementing the proposed co-creation activities

According to above selection criteria a total of 31 papers were selected. Among them 5 papers addressed to young people and children/parents were also eliminated of our study, and 3 was not focused on digital solution, providing at the end a total of 23 papers to be analysed.

3.2.4. Results of previous co-design activities

23 papers addressed to co-design/co-create digital solutions with at least one of the ValueCare target groups were analysed in terms of the activities used and participants involved. The result of this analyses is summarised in the following table (Table 8):

Target group	Co-design activity	Target	Focus	Tips
Patients	Survey	Cancer (Kildea et al., 2019)	To design person-centred patient portal smartphone app	Developed in waiting rooms
		Rheumatoid Arthritis (Grainger et al., 2017)	To gather feedback about a prototype	1-month testing Online survey
	Interviews	Rheumatoid Arthritis (Grainger et al., 2017)	To explore technology use, app functionality, barriers and facilitators to app use, and potential impacts of app implementation on service provision and experience.	9 - 20 interviews
		Heart failure (Woods et al., 2017)		1-month testing
		People living with HIV (Marent et al., 2018)	To gather feedback about a prototype	14 days testing
	Focus groups	Cancer (Kildea et al., 2019)	To test the prototypes (features and usability of the mobile app)	1 focus groups with 3 patients + 1 focus group with 5 members of the patients' committee
	Workshops	Chronic conditions (Jessen et al., 2018)	Co-design	2 workshops with a total of 22 participants
		People living with HIV (Marent et al., 2018)		7 workshops
Patients and public	Workshops	Motor neurone disease (Hobson et al., 2018)	Early ideas presentation	2 workshops Written feedback at the end
Patients and families/ caregivers	Individual feedback	Cancer (Kildea et al., 2019)	End-user testing	
	Interviews	Nursing homes (Curtis & Brooks, 2020)	Understanding the Digital health technology, experiences, and potential benefits	Face to face and audio recorded Resident and their relative were interviewed together

		Motor neurone disease (Hobson et al., 2018)	Service-user consultations	**Semi-structured interviews** 1 patient and 1 caregiver
		Heart failure (Woods et al., 2017)	Understanding daily life living with, and self-managing, heart failure	**Ethnographic interviews** Empathise phase
		Dementia (O'Connor et al., 2019)	To co-designing a mobile application	**In-depth interviews** In person (2 patients + 2 relatives)
Families / caregivers	Interviews	Dementia at the end of life (Davies et al, 2019)	To test the prototype website	11 caregivers
	Focus groups	People affected by Psychosis (Sin et al., 2019)	To perform iterative consultation	2 focus groups of 2 hours each: 1st focus group: feedback about the first alpha-build of the intervention, the flow and readability content 2nd focus group (not with the same caregivers): feedback on an online second alpha-build of the intervention
Patients and health professionals	Workshops	Diabetes (Giordanengo et al., 2018)	Co-design the "knowledge-base module"	1. Patients (5) 2. Health professionals (4) 3. Patients and health professionals (9) 1 and 2 in parallel
		People living with HIV (Marent et al., 2018)	Development of an mHealth platform	3 mixed workshops
		Parkinson disease (Revenäs et al., 2018)	Design an eHealth service for co-care for Parkinson disease	4 half day co-design workshops with patients and health professions: 1,2 and 3 capturing needs and generating ideas 4 prototype demonstration
		Motor neurone disease (Hobson et al., 2018)	To test potential telehealth patient app	2 workshops - 3 MND patients, 6 carers or ex-carers, and an MND specialist nurse. 2 patients attended with carers Session: icebreaker used puzzles and games to introduce the group and established aims and rules of the workshop + patient journey mapping exercise + personas
	User testing sessions	Mental health service (LaMonica et al, 2019)	Feedback on existing and newly designed functionality	Quarterly sessions + baseline in 12 months

	Semi-structured interviews	Cardiovascular disease (Bonnet et al., 2019)	To obtain website feedback	1 health professionals and 2 patients
Health professionals	Interviews	Rheumatoid Arthritis (Grainger et al., 2017) People living with HIV (Marent et al., 2018) Nursing homes (Curtis & Brooks, 2020) Antibiotic stewardship information system (Maia et al., 2018)	To explore technology use, app functionality, barriers and facilitators to app use, and potential impacts of app implementation on service provision and experience. Understanding the Digital health technology, experiences and potential benefits (Curtis & Brooks, 2020)	2- 11 interviews Face to face and audio recorded (Curtis & Brooks, 2020)
		Mental health (Ferr et al., 2019)	Co-production in mental healthcare planning	**In-depth interviews** 32 min average; telephone; recorded verbal consent
		Mental health service (LaMonica et al, 2019)	To evaluate and monitor the impact of embedding the technology-enabled solution in the service	**Semi-structured interviews** Quarterly + baseline in 12 months combined with workshops and surveys with the same timeline
	Workshops	People living with HIV (Marent et al., 2018)	Co-design	4 workshops
		Mental health service (LaMonica et al, 2019)	To evaluate and monitor the impact of embedding the technology-enabled solution in the service	Quarterly workshops + baseline in 12 months combined with surveys and semi-structured interviews with the same timeline
		Nursing homes (Curtis & Brooks, 2020)	To discuss a practical, evidence-based process for digital health technology implementation in nursing homes	2 co-creation workshops
	Survey	Mental health service (LaMonica et al, 2019)	To evaluate and monitor the impact of embedding the technology-	Quarterly surveys + baseline in 12 months combined with workshops and semi-structured interviews with the same timeline

			enabled solution in the service	
		Antibiotic stewardship information system (Maia et al., 2018)		
	Meetings	Cardiovascular disease (Bonnet et al., 2019)	Codesign of content	Small group
		Cancer (Kildea et al., 2019)		6 health professionals + 1 administrative staff Weekly meetings
		Motor neurone disease (Hobson et al., 2018)	Consultation with regular meetings and review telehealth content and the software	7 health professionals
		Antibiotic resistance (Simones et al., 2018)	Innovativ surveillance and clinicial decision-support system for antibiotic management	Problem identification (observation) + definition of objectives + design and development
	Conference	Cardiovascular disease (Bonnet et al., 2019)	Website	Presentation, question/answer session and a tablet placed in an exhibition room
	Presentations	Cancer (Kildea et al., 2019)	awareness + feedback and concerns + seek support for the app and education material	From on-the-floor care providers to senior management and the board of directors of the institution
	Prototype /feasibility study	Cardiovascular disease (Bonnet et al., 2019)	Website	Using final solution for 1 month (survey for collecting data).
Patients, caregivers and health	Interviews	Heart failure (Woods et al., 2019)	Co-Design of a Mobile Health App	In person and by email (11 interviews)
Managers	Interviews	Dementia (O'Connor et al., 2019)	To co-designing a mobile application	**In-depth interviews** By telephone
		Mental health (Ferr et al., 2019)	Co-production in mental health care planning	**In-depth interviews** 32 min average; telephone; recorded verbal consent
		Nursing homes (Curtis & Brooks, 2020)	understanding the Digital health technology, experiences, and potential benefits	Face to face interviews and audio recorded
Multi-stakeholder	Design / co-production workshops	Heart failure (Woods et al., 2019)	To co-designing a mobile application	Design sprint activities (lightening demos, idea matrix, greatest hits and solution

			sketch) resulted in a storyboard of the app on a whiteboard. 7 health professionals + 7 patients + 4 caregivers
	People affected by Psychosis (Sin et al., 2019)	Coproduction workshops	Expert advisory Board: 3 individuals with lived experience of psychosis, 3 carers, 1 health care professionals, 4 researchers, 1 voluntary organisations, and 2 eLearning experts (total 14 participants in 4 workshops along 12 months)
Multidisciplinary consensus meeting	Older patients with colorectal cancer (Nguyen et al., 2018)	Evaluation of pre-existing website, prototype website development and evaluation	9-11 patients + researchers + physicians for evaluating the pre-existing website 6-20 patients + researchers + physicians + nurses + administration for redesigning 10 patients + researchers + physicians + nurses + administration for usability testing
Research development group consisting	Dementia at the end of life (Devies et al., 2019)	First step in the co-production of the prototype website	3 academic experts in dementia, end of life, carers and digital health; health care practitioners (4 general practitioners, 1 academic nurse, 1 Admiral nurse); 2 members of a dementia charity organisation, and 1 caregiver
Programme committee	Diabetes type 2 (Vluggen et al., 2018)	To foster co-creation	3 times meeting during 18-months program development (practice nurses, diabetes nurses, dietician, internist, general practitioner, health scientist, e-Health expert, and patients)
Design box	Persons with physical disabilities (Terry et al., 2019)	Needs and key elements for the app	
User-testing		To identify technical errors and gather feedback on usability/accessibility	

Table 8. Search results

Task 3: Design of the guidelines for pilot sites

With the information gathered in previous tasks and with the consultation to partners developing the ValueCare concept and IT solution, partners collaborating in this document have developed the guidelines that support pilot sites to implement co-design activities. In this process:

1   The steps to implement the co-design activities in pilot sites are based on the principles of Experience-Based Co-design.
2   Although each pilot site can choose the best way to gather information from the target groups using the co-design activities proposed at the beginning of this document, some activities are recommended based on the literature review made.

3   Questions to be addressed in the co-design activities to each target group have been shared and completed with ValueCare partners responsible to develop the ValueCare concept and IT solution.

4   Some annexes are included to facilitate the work of pilot sites in form of checklists and reporting documents.

4. Guidelines to develop co-design activities in pilot sites

ValueCare proposes to follow the principles of **Experience-Based Co-design** that involves the following stages (Bate and Robert, 2007a) (Figure 4):

Figure 5. Co-design process

(1) setting up the project;
(2) gathering staff experiences;
(3) gathering patient and carer experiences;
(4) bringing staff, patients and carers together in a first co-design;
(5) sustained co-design work in small groups formed around priorities (typically 4–6); and
(6) a celebration and review event.
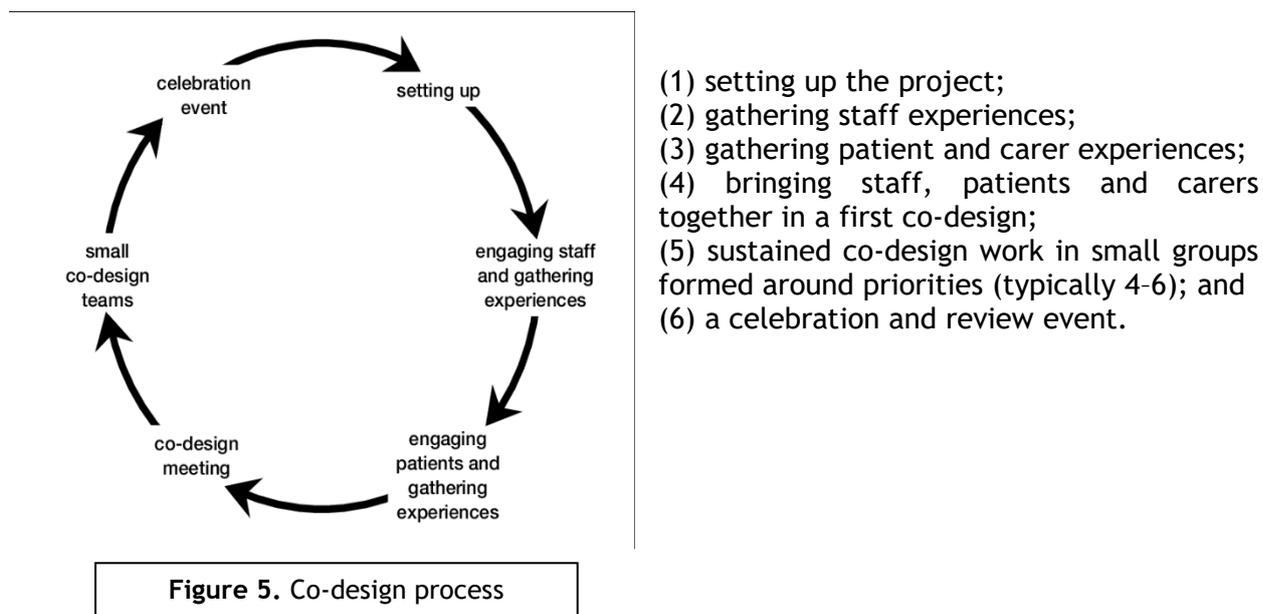
(1) Setting up the project: the framework to implement the co-design activities is already defined by the ValueCare project. In concrete,

✓ 1st round of co-design activities is addressed to define the concept of value, the treatment pathways and the desired IT support solution; and

✓ 2nd round of co-design activities will be addressed to merge-versions and identify improvement points of ValueCare solution based on target groups' needs.

Note that pilot sites should involve all the target groups at least two times along the project implementation as part of the co-design process. Now pilots should implement co-design activities to define the concept of the value, the treatment pathways and the desired IT support solution (1st round).

(2) and (3) Gathering staff, patient and carer experiences: in the initial stages of the project, the ValueCare target groups will be presented with the relevant information on the project, the planned activities, their objective and their expected role. As part of this, leaflets will be made available for the pilot sites (see WP6 on communication).

As described previously, ValueCare aims to co-design with **three target groups** the ValueCare concept and IT solution. In this sense, pilot sites can choose the co-design activities presented along this deliverable that better respond to their characteristics and ways of working, although below there are some recommendations collected from previous experiences (Table 9). Please take into account that during this first round of co-design activities, the activities will be implemented independently for each target group (no mixing activities are foreseen at this stage, but patients and families):

Target group	Co-design activity	Tips
Patients	Survey	Developed in waiting rooms (Kildea et al., 2019)
		Online survey (Grainger et al., 2017)
	Interviews	To explore technology use, functionality and barriers (Grainger et al., 2017)
		To gather feedback about a prototype (Marent et al., 2018)
	Focus groups	To gather feedback about a prototype (Kildea et al., 2019)
	Workshops	2 workshops (Jessen et al., 2018) **Used in co-design process with patients with chronic conditions**
Families	Individual feedback	End-user testing (Kildea et al., 2019)
	Interviews	Nursing homes (Curtis & Brooks, 2020)
Patients and families	Focus group	Iterative consultation (Sin et al., 2019)
	Interviews	**In-depth interviews -** In person (2 patients + 2 relatives) to co-design a mobile app and test website **Used in co-design process with patient with dementia and caregivers; and caregivers of dementia patients at the end of life**
Health and social care practitioners	Interviews	**In-depth interviews -** telephone; recorded verbal consent (Ferr et al., 2019) **Semi-structured interviews -** Quarterly + baseline in 12 months combined with workshops and surveys with the same timeline (LaMonica et al, 2019) **Used in co-design process with health professionals in mental health service**
	Workshops	Quarterly workshops + baseline in 12 months combined with surveys and semi-structured interviews with the same timeline (LaMonica et al, 2019) **Used in co-design process with health professionals in mental health service** 2 co-creation workshops in nursing homes (Curtis & Brooks, 2020)
	Survey	Quarterly surveys + baseline in 12 months combined with workshops and semi-structured interviews with the same timeline (LaMonica et al, 2019) **Used in co-design process with health professionals in mental health service**
	Meetings and conference	Small group (Bonnet et al., 2019) **Used in co-design process with health professionals working with cardiovascular disease**
	Prototype / feasibility study	Using final solution for 1 month (survey for collecting data) (Bonnet et al., 2019) **Used in co-design process with health professionals working with cardiovascular disease**
Managers	Interviews	**In-depth interviews** by telephone (O'Connor et al., 2019; Ferr et al., 2019) **Used in co-design process for dementia patients and mental health**

	Face to face and audio recorded in nursing homes (Curtis & Brooks, 2020)

Table 9. Overview of the systematic review results

Independently of the activity carried out, **pilot sites should involve all the target groups at least two times along the project implementation as part of the co-design process**. In these activities, partners should respond to the following questions (the questions below will be addressed during the first co-design activities and will be updated later, pilot can address all questions in one or more activities). Please consider that the questions below are just a starting point. It is anticipated that each pilot site will adapt and tailor the questions as appropriate.

4.1 TARGET GROUP: Older people

OVERALL AIM: to co-design the ValueCare App and concept

QUESTIONS:

ValueCare concept	ValueCare IT solution (IT mobile app)

1 What are your health and social care priorities (for example XXX)? Could you rank them or give a score from 1 to 5 to them? (1 less value and 5 more value)
2 To what extent do you experience difficulties managing your health? If so, how could you be supported to better manage your health (for example XXX)
3 What kind of information about your health would you find useful to access and in what format? What has worked/not worked for you in the past?
4 Would you like to influence your actual and future care by personalising the service/treatment you are receiving or will receive?
5 Are you willing to change your lifestyles/behaviour/routines to positive influence in your health?
	About the smartphone:
	1 Do you have a smartphone? How often do you use it? for what purpose do you use it? What do you find difficult to use: touchscreen, virtual keyboard, small screen, application, swipe..? Can you also elaborate on the elements you enjoy when using your smartphone?
	About Apps:
	2 What kind of apps do you have on your phone? How do you manage to install them? Which apps do you find particularly useful? Which app do you use everyday? why these apps in particular? which one is your favourite app? why?
	3 Did you change/ adjust your phone's "look" after it was bought so that it was more accessible/ easier to use? (for example did you have to increase the font, the contrast...?)
	4 If you had an app to help you manage your health
	  ► what would it do to support you? (direct chat with your doctor, reminder to take your medication, advice on physical activity/exercise adapted to my physical conditions, nutrition tips, etc.)
	  ► what kind of characteristics (content and layout) should it have? (provide useful contents, to help me in self-organisation, to be secure and safe, to be friendly...)
	5 Do you have medical devices at home? (e.g. panic button) which one(s)? What information do you obtain from them (blood pressure, glucose levels, temperature...)? How often do you use them? (measure your temperature, blood pressure..)

Table 10. Questions for older people

4.2 TARGET GROUP: health and social care practitioners

OVERALL AIM: to co-design the ValueCare Dashboard, app and concept

QUESTIONS:

ValueCare concept		ValueCare IT solution	
1	When it comes to creating 'value' in the work that you do (health and care), describe the three most important attributes.	1	Have you used eHealth technology before within uour work? What was your experience?
2	Assuming these three attributes are in place, what kind of impact do you expect on your daily work? (e.g. less burden, quality of work and own quality of life...)	2	What health indicators would you like to see in the ValueCare dashboard collected from the ValueCare app? (related to the app functionalities: vitals, physical activity...)
3	Would you like to personalise the care you provide to your older patients? If so, how?	3	Do you want to mix the data collected from the app with your existing medical data? How?
4	How would you like to monitor the older people you work with?	4	How would you prefer to access the dashboard?
5	Would the ability to communicate more closely with your older patients benefit you? How? Would it benefit them?	5	How would you prefer to see the data presented?
		6	Would you like to interact with the older person / patients (e.g. sending reminders to older person app)?
		7	How could the dashboard improve the integration of the care (health and social) provided to older people / patient?
		8	Thinking about what a user-friendly app should look like, which are the main features that it should provide?
		9	In which ways do you prefer to interact with a supporting application? By texting? By speech, other ways?
		10	Are the any aspects at your hospital that would be a facilitator or challenge to using eHealth technology?

Table 11. Questions for health and social care practitioners

4.3 TARGET GROUP: health and social care managers

OVERALL AIM: to co-design the ValueCare Dashboard and concept

QUESTIONS:

ValueCare concept		ValueCare IT solution	
1	What does 'value' mean to you when it comes to health and care? What do you understand by "value-based healthcare"?	1	How would you prefer to access the dashboard?
2	What kind of impact do you expect value-based health care delivery will have on your work/organisation? (e.g. less burden, quality of work and own quality of life...)	2	How would you prefer to see the data presented?
		3	Do you want to interact with the health professionals?
3	And in the care (health and social) system)?	4	How could the dashboard improve the integration of the care (health and social) provided to older people?
4	What would be the main gain that value-based interventions could provide to your organisation?	5	How do you measure and consider the success of VBHC implementation within the existing health and social care services at local level?

Table 12. Questions for health and social care managers

As detailed in the section on the DART model, at this stage of the project, bilateral activities will be implemented, and in later stages of the project, joint co-design activities among target groups will be organised. So, the next phases of the EBCD will be detailed in the updated version of this deliverable.

5. Conclusions

This deliverable has been elaborated to provide the 7 pilot sites of the ValueCare project the tools to implement the co-design activities for each of the ValueCare target groups. On this basis, the report provides:

- Tools (activities) to involve the end-user in the ValueCare project with practical information on how to organise different co-design activities and suggestions on concrete activities to be included in the agenda, also considering the possibility to organise some of them online.
- Questions to be discussed with each ValueCare target group in the co-design activities. These questions should be adapted by each pilot site to their context. Those questions are needed to provide the required information for the definition of the ValueCare concept and digital solution.
- Supporting documents (checklists and reporting sheets) to implement and report the co-design activities.
- The link between the co-design sessions and the engagement strategy developed in the deliverable 2.3.

Consequently, this report is elaborated as supporting tool to facilitate the work to pilot sites in implementing the co-design activities involving **three main target groups** with the following required numbers:

1. **Older people and their families**: 20 older people and 20 informal caregivers.
2. **Health and social practitioners**: 10-15 professionals.
3. **Health and social care managers** with decisions in health and social systems (integrated care): 5 health and social care mangers also considering ICT managers (Chief of the ICT departments of local stakeholders such as Health or Social services, Municipalities).

ValueCare proposes three types of co-design activities: **national seminars, world cafes and focus groups.** Pilot sites can use them for the target group and content they consider according to their normal procedure. At the end, **all pilot sites should gather the relevant content and involve all the target groups**, but the process to collect the information and involve them can be adapted to the normal procedure and context of each site. Moreover, this report also suggests some **extra activities** to be performed in-person or online to continue with the project activities during the COVID-19: surveys, interviews, social networks, video. Additionally, activities to be performed inside the agenda of those events have also suggested (SWOT, needs Assessment Exercise; tree Diagrams, scenarios, patient journey, interactive backcasting). The strengths and weakness of each activity are described along the document, in order to provide all the information to pilot sites to take the best-informed decision. A summary is presented below (Table 13).

Co-design activity	Strengths	Weaknesses
Video to socialise the ValueCare project	Virtual	Not access to people without Internet or with low-digital skills
Interviews	Can be implemented online Flexibility Useful way to test ideas and gather general feedback	Representativeness Number of interviews needed and personal resources
Online survey	Can be implemented online Minimal costs User decides when to answer	No open to clarifications Not access to people without Internet or with low-digital skills

	Easy analysis	
National seminars	Great number of stakeholders together Possibility to organise parallel sessions	Resources (time, coffee breaks, and renting rooms) Need to have an attractive agenda Dissemination
World Café	Relaxed and open conversations	Good moderator needed Resources (time, coffee breaks, and renting rooms)
Focus groups (online)	Relaxed and open conversations Bottom-up approach Facilitate the interaction (perspectives and inputs)	Resources (time, coffee breaks, and renting rooms) -> not if organised online Dealing with reluctant participants

Table 13. Co-design activities

In summary, the steps are defined in the following image:

Select the target

- Select the target group and the activity (please be aware that each pilot site should gather information to all target groups combining the co-design activities according to their context and normal procedure).

Contextualise

- Adapt the questions according to your context

Guidelines

- Follow the guidelines provided for each activity. Please do not forget ethical issues (such as the informed consent) and to check the security / safety normative in your region.

Implement and track

- Implement the activity and record feedback.

Report

- Report the activity implemented using the templates provided in this deliverable (annexes).
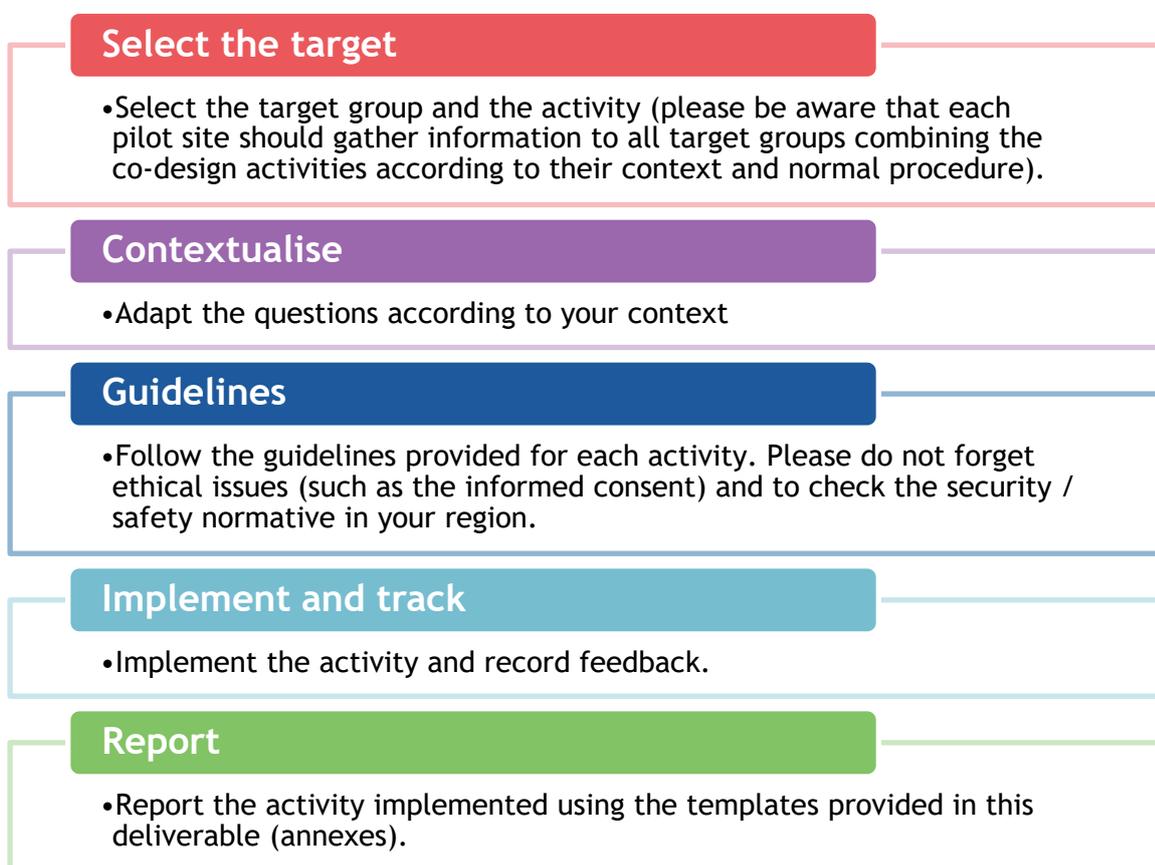
Figure 6. Steps to organise the co-design activities

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Annexes

Checklist for in-person co-design activities

Items	Completed / Yes	Pending / No
Identified the group to be involved in the activity		
Applied the recruitment procedures and the selection criteria suggested in the protocol for every target group addressed (older people, health and social practitioners, health and social managers)		
Sent out the invitation to possible participants		
Shared the information package together with the invitation, including: · The objectives of the project and the meeting · Logistic information about the venue / virtual space · Any reimbursement forms in case of travel expenses · Consent form · Contact person details · List of topics to be discussed / expectations		
Checked the heterogeneity of the final group and its representativeness		
Made sure the number of participants is the right one (around people 8 for focus groups / max 5 per „cofee table group") to have a rich and useful discussion		
Defined an initial timing of the focus group		
Developed 10 questions to be asked during the activity (adapted from the questions proposed in this deliverable for each target group)		
Made sure the questions are clear, short and focused, but open-ended (starting with "how", "why", "what") and include probe questions, exploration questions, exit questions		
Appointed a coordinator for the session		
Appointed a note taker for the session		
Booked a venue (cirtual or physical) which is accessible to all participants		
Made the venue comfortable (provided water, prepared food…) – if relevant		
Cheek tge security/safety issues according to your local normative		
Addressed hearing and vision impairment		
Got the materials to run the activity (flip charts, pens, papers...) – if relevant		
Checked consent form of each participant prior to start		
Asked the permission for recording the session		
Recorded the session		
Informed the participants on the next steps following the activity		
Shared the results of the session with the participants		

Templates for the informed consent pack

NOTE: This is just a proposal. In case pilot sites have their own templates, they can use them. From other side, in case that pilot sites do not need to use a informed consent they can omit this annex.

Informed Consent Form for participation in

Dear Sir / Madam,

You have been invited to take part in this evaluation study, under the European research project ValueCare. Its main objective is to achieve greater efficiency in the use of resources and in the coordination of health and social care. To this purpose, ValueCare intends to deliver an outcome-based integrated care app and platform, specially built to older people, aimed at improving their quality of life (as the one of their families), and yet the satisfaction and wellbeing of their health and social care providers. Through a clarification session, you will receive detailed information about this study in a personalized way.

This information folder is organized in two parts:

• Part I: General information about the study

• Part II: Informed Consent (to be signed if you agree to participate in the study)

You must know that, if you do not wish to participate, this will not affect your relationship with [FILL organization name] in any way, nor carry out any negative consequences for you. In case you agree to participate, you are also free to leave the study at any time, without the need of further justification. Your choices and rights will always be respected.

The engagement of people in research projects is essential to deliver useful and relevant results. In order to do so, we need you to provide your written consent to cooperating with us. Please read carefully the Part I of this information folder, before making a decision. You can also ask for the clarifications you may need, regarding any question that does not have a clear and complete answer in this document.

Please, do sign Part II of this information folder only if:

• You fully understood the type and procedure of the evaluation study.

• You are willing to give your consent in writing.

• You understand your rights as a participant in this research project.

PART I: GENERAL INFORMATION

1. What is the purpose of this evaluation study?

This evaluation study is part of the activities of the research project – ValueCare, co-funded by the European Commission in the Horizon2020 programme [Grant Agreement number 875215].

The overall objective of the ValueCare project is to support Europe's ageing population by building a secure, customizable and scalable digital solution for integrated health and social care delivery, to be tested and evaluated through 7 large-scale pilots in Europe:

- The Netherlands [Rotterdam]
- Portugal [Coimbra]
- Italy [Treviso]
- Greece [Athens]
- Spain [Valencia]
- Croatia [Rijeka]
- Ireland [Cork/Kerry]

The main purposes of this study are:

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 (as the one of their families and formal caregivers) based on value-based methodologies and supported by digital solutions;
2. To contribute to the sustainability of health and social care systems in Europe;
3. To provide a secure, scalable and robust digital solution for integrated care.

2. Who is the responsible for the study in [FILL pilot site]?

The project has the participation of [FILL institution name].

[FILL institution name] is the responsible for the activities in [FILL pilot site].

All contacts are available below in section 10 of this document.

3. How will this study work?

Co-creation phase

We wish to collect your needs and wishes to ensure that the results of the project will be of interest to older adults and their caregivers.

[FILL number] participants will be involved in [FILL name of pilot site], through [FILL focus group session, world café, seminar, individual interviews, phone calls/telcos].

The interview/focus group/world cafe questions will focus on your personal opinions on different aspects.

If you agree to participate in the study, we will make an appointment with you. This is expected to take about [FILL hours/min].

Before signing, please bear in mind that, due to the Covid-19 pandemic and emergency state restrictions, in case of a telephone or other remote interview, your consent may be recorded, in a preliminary phase, by using a voice recorder. This recording will only be kept until this consent form is duly signed, being destroyed just after.

The questions and answers may also be recorded, so that the researchers can later on go back to what was said during the interview. In this case, the interview data will be transcribed (written down), translated into English and analysed. All personal information that could lead to your identification will be separately recorded, so that there is no connection between your answers and your identification. All the answers to the questions are only analysed, treated and shared in a completely anonymised manner.

4. What are the benefits of your participation in the study?

By participating in this study, and providing your opinions, you are contributing to the development of a system of services that aims to support you as you age.

It is possible that your participation in this study will not directly benefit your health; however, by participating and providing us with your feedback, you will contribute to develop an efficient and practical integrated care support system not only for older adults, but also for their formal and informal caregivers. This assessment will allow us to better define the development of the ValueCare platform, so that it turns out useful and adequate for you and other older adults.

5. Are there any risks, discomforts or side effects related to your participation in this study?

Since it is a non-invasive study, no significant risk is predicted. However, if you find any doubt, difficulty or problem, immediately contact the Main Researcher for the study in [FILL pilot site].

6. Is there any cost involved in participating in the study? Is there any financial reimbursement for participants?

Absolutely no costs or any other financial consequences will arise for you as a participant of this study. Participants will not receive any financial compensation for participating in the study.

7. Data Protection

In what way will the collected data be used?

All data will be protected against unauthorised access. The data collected about you will be safely stored by [FILL institution and country], completely separated from your name and from this consent form.

Only completely anonymised data will be shared with other consortium partners (all inside the European Union) for aggregated analysis. This means that your name will not be used in connection with any of the data collected, and there will be no link between your answers and your personal information. In this way, it will not be possible for any other researcher to identify your responses.

Any data shared with other researchers and research institutions that are not part of the consortium will be completely anonymised as well. Likewise, any publications that may result from this study will not include any personal data that may lead to your identification.

You can oppose your consent to the processing of your data at any time. After this decision, no further data from you will be processed.

The research team involved in this study ensures that the resulting material will be stored in a safe, anonymized location, no later than [FILL number] years after the completion of the study. Moreover, all members implicated in this study are bound and guided by the European data protection standards (GDPR).

If you have any further questions about the processing of your personal data, please contact Mr/Mrs [FILL person in charge of data processing in the institution].

8. Early withdrawal of your participation in the study

You can interrupt your participation at any time, without having to provide any explanation. The withdrawal will have absolutely no negative consequences for you at [FILL institution].

Even after completing the study, you have the right to express the will that your data is removed and deleted, except for those that have already been published or used in reports, that cannot be redeemed or changed. To request the removal or deletion of your data, please contact the investigator in charge of the project.

Either to interrupt your participation in the project or to request the deletion of your data, please contact the project manager, by phone or email. You can find the contacts at the end of this document.

9. Possibility to discuss other issues

If you have any further questions about the project or about your participation in it, you can contact the Main Researcher at [FILL institution] (see contact details below) now or later.

You can also contact the Coordinator of the project, responsible for it at international level – [FILL name, institution, place, email address]. In addition to the researcher responsible for the study and the person in charge of the data processing in [ADD pilot site], you have the right to complain to the [FILL country] National Data Protection Commission about the processing of your personal data through [FILL email, telephone].

10. Contacts

Main Researcher responsible for the ValueCare study at [FILL institution name]

Name – [FILL]

Contacts – [FILL telephone number] | [FILL email]

Data Protection Officer at [FILL institution name]

Name – [FILL]

Contacts – [FILL telephone number] | [FILL email]

Project Coordinator at international level

Name - [FILL name, institution, place, email address, telephone]

If you wish to participate in this study ValueCare, we would like you to complete **Part II** – **Informed Consent Statement** and to keep this information folder.

PART II: INFORMED CONSENT STATEMENT

I have been thoroughly and comprehensively informed about the meaning, objectives and scope of the ValueCare [strike out what does not apply] co-creation session / pre-evaluation trial / evaluation trial, as also about the resulting requirements or any potential risks and impacts to myself and my life. This information was given by Mr. / Mrs [FILL name] _____.

I have read/it has been read to me [strike out what does not apply] the above [FILL number] pages of information. I have had the opportunity to ask questions about it, and any questions that I have asked were satisfyingly answered. Consequently, I am able to confirm that I have understood the provided information.

I will adhere to the necessary requirements for the implementation of the study, while reserving the right to withdraw my voluntary participation at any given time, implicating no negative consequences to myself.

I consent voluntarily to participate in this research project:

☐ I declare my consent to take part in this study.

☐ I declare my consent to recording (including interview voice recording and transcription), transferring and storage of my personal data, as described in sections 3 and 7.

☐ I declare my consent to the sharing of completely anonymized data with organizations outside the ValueCare project for the established period, as defined in section 7.

Name of the participant: _____

ID number: _____

Identification Code: _____

I have received a copy of this informed consent form for participation in the ValueCare study. The original form will be stored at the care service provider.

Signature of participant: _____

Day/month/year: _____ / _____ / _____

TO BE COMPLETED BY THE RESPONSIBLE OF THE STUDY IN THE ORGANISATION

I, _____ declare that the participant spontaneously signed and agreed to his/her participation in this study.

I also declare that:

☐ I provided the participant with all the necessary information for the understanding of this study, its purposes, procedures, possible risks and benefits.

☐ I confirmed that the participant understood the provided information.

☐ I provided time for reflection and the opportunity to ask questions about the study.

☐ I have not exercised any coercion or otherwise influenced his/her consent.

Signature: _____

Date: _____ /_____ /_____

PART III: REVOCATION FORM

TO BE USED ONLY IN CASE YOU WISH TO LEAVE THE VALUECARE STUDY

Dear Sir / Madam,

You have been invited to take part in the ValueCare study, a funded European research with the main objective of achieving greater efficiency in the coordination of health and social care, through the creation of a customizable and outcome-based digital tool for integrated care.

However, you withhold the right to interrupt your participation at any time, without having to provide particular explanation, and not being subject to any negative associated consequences for you at _____ [FILL institution]. In case you intend to exercise that right, please fill in your data below, if possible, in your own handwriting.

I, Mr/Mrs [strike out what does not apply] …………………………………………………………….., with the ID number …………………………, REVOKE the consent previously given for the inclusion of my data in the ValueCare research study, without having received any kind of opposition or undesirable consequences because of it.

[INSERT location and date]

_____, _____ of _____ of 20_____.

[If possible, please sign in your own handwriting]

The participant: _____

Template for reporting co-design activities at pilot sites

GENERAL OVERVIEW:

Pilot site	
Promoter	
Target group addressed	
Nº of participants (target group)	
Other stakeholders involved	
Nº of stakeholders participating	
Type of co-design activity implemented	
Date	
Duration	
Aim of the activity	
Achieved goals	

ACTIVITY INVITATION: *Please report on how you recruited the participants and, in case, copy the emails, pots, etc. used.*

ORGANISATION: *Describe the problems faced in implementing the initiative, how were they overcome, and the problems that remain to be solved. Provide a summary of tools, methods, and/or benchmarks that were used for assessing performance*

AGENDA: *Please copy here the agenda of the event.*

CONTRIBUTIONS FROM PARTICIPANTS: *Please add here the feedback received from participants.*

Inputs for the ValueCare concept	
Inputs for the ValueCare app	

LESSONS LEARNT: *Describe the three or four most important lessons learnt and how these lessons have been or are being incorporated in your pilot in this or next co-design activities. Describe how these lessons can be also considered in the guidelines for co-design activities.*

MISSING GUIDELINES: *What did you miss from the guidelines document for co-design activities that you would like to have in the next version of this document?*

PRESS RELEASE – LINKS AND SOCIAL NETWORKS USED:
►

REGISTRATION LIST

PICTURES: *Please attach to the report the registration lists and pictures.*

Registration list

Title of the event: Date: Place:		By stating the information in these fields, I declare that I give the explicit consent to NAME PARTNER to store my personal data for the purposes of the project related to the events it organizes, and the latter undertakes not to provide this information to third parties persons. *		Check this box if you agree to be informed about other events by email and/or phone	
Name and Surname	**Organisation & position**	**E-mail**	**Phone number**		**Signature**
				☐	
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*In line with the GDPR – General Data Protection Regulation