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D2.3 Engagement strategy for the ValueCare concept co-design - Report on strategies to involve end-users in pilot site co-design activities.

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Abstract
The deliverable describes the strategies to engage end-users in the co-design activities and in the piloting of the ValueCare project's implementation. The aim is to define the strategies needed to engage the main target (stakeholders, older people, families, professionals and managers) in the co-design activities and the needed profiles. A methodology to develop the engagement strategies that pilot sites will adapt to their national contexts and target groups will be provided. In this deliverable the focus is the description of powerful strategies for engagement that will be the first actions to start the co-design activities to co-create the ValueCare framework of integrated care to test in the pilots.

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Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise.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

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EXECUTIVE SUMMARY

This deliverable, **2.3 Engagement strategy for ValueCare concept co-design** defines engagement strategies and the target groups that will be involved in the ValueCare co-design activities.

It is addressed to provide pilot sites the guidelines to develop the engagement strategies in order to give a methodology to increase users' engagement in either their own health, social care and support services as a recipient or deliverer.

This deliverable outlines the rationale and strategies for engaging the ValueCare project's three target groups: 1) care recipients 2)informal caregivers and practitioners 3) public and private care sector decision makers in charge of the adoption of the project's results and how they can be exploited.

The report is organised as follows:

- **Section 1** - an overview of the existing evidence on engagement strategies in social innovation processes applied to health, followed by a description of specific engagement characteristics required for each target group
- **Section 2** - a description of the value-based model for integrated care and how this needs to be taken into account in the engagement strategies for each target group
- **Section 3** – a summary description of the 7 large-scale pilot sites
- **Section 4** – an in-depth description of ValueCare's end-users and main stakeholders
- **Section 5** – an overview of ValueCare's methodology for engaging end-users in co-design activities in a way that is appropriate according to each target group's needs. The methodology is based on a literature review on the most effective engagement approaches available to date.
- **Section 6** – a 'toolkit' with different engagement tools available to pilot sites to stimulate end-users as "agents" in the critical reflection of the existing care pathways and the proposal of solutions to create value according to the guiding question: what matters to the care-recipient?

It is important to remark that this deliverable is focused on engagement strategies of the main target groups, instead, the **2.6 Report on co-design activities for the ValueCare concept** is focused on co-design activities and how to involve ValueCare target groups in this process, although they are both strongly connected.

The main finding that has been reached out is that the local engagement strategy and its deployment should be contextual sensitive and it should move along a continuum from the consultation to the full partnership, with the end users and the stakeholders, based on the three main dimensions: the patient profile, the organizations characteristics and the societal cultural elements.

The guidelines proposed in this deliverable are dynamic and will be adapted, updated and improved along the project implementation integrating the feedback received and the modifications needed as a consequence of its execution.

The table below describes how this report on engagement strategies will help inform other ValueCare activities and outputs.

Deliverable	Relation

D2.1 ValueCare concept [EMC] (M48) - Report defining the ValueCare concept.	D2.1 concerns the definition of the Value-Based framework. D2.3 will provide the first inputs from end-users in terms of their understanding and expectations of Value-Based care
D2.2 Identify data needed [EMC] (M24) - Report with the clerical and clinical data needed and timeline.	D2.2 focuses on identifying data needed to implement the use of AI and ML to feed the Virtual Coaching support mediated by ICT. Engagement activities will need to help identify ICT requirements and ensure data flows between services.
D2.4 Report on the co-design activities for the ValueCare concept [KVC] (M6, M16, M32) - Guidelines to implement the co-design activities in pilot sites.	D2.4 depends on the actions and results of D2.3. After having engaged the main targets, co-design will take place following the methodology that will be defined into D2.4. D2.3 methodology will be useful to pre-recruit stakeholders for co-design activities and it will motivate and involve the targets at a local level.
D3.2 Technical Requirements of architecture [VIDAVO] (11TM14) - Conceptual design of ValueCare technical architecture.	The definition and development of ML (Machine Learning) /AI (Artificial Intelligence) algorithms will start during the events that the D2.3 has foreseen. There will be presented the logical ICT framework of ValueCare towards the main players. They will be led to solve the issue of the "ontology" preparation and feed of the ML along the Project implementation
D4.1Guidelines to adapt the ValueCare model to pilot sites [EMC] (M14) – This report will adapt the ValueCareconcept to practical guidelines for pilot sites to adapt the concept to their target groups and context.	D2.3 will set up the logical framework that each Pilot will implement locally as foreseen by D4.1
D6.2 Dissemination and Communication Plan [IFIC] (M5) – Detailed communication and dissemination plan adapted and tailored to ValueCare project and pilot sites.	D2.3 will be based on the "core message" and the communication tools provided by the D6.2: web site, Project's visual identity and the social media campaign that will be organized in strong coordination within the Pilot sites.
D7.1 Innovation ideas raised from ValueCare implementation [ECHA] (M36) – Report with business ideas collected from the ValueCare implementation	D7.1, that is about innovation management, will be an essential link with the D2.3. Thanks to D7.1 each Pilot would be able to identify, with specific and strategic criteria, the locals' main care players (public/private), that could join and support the ValueCare deployment and that could be interested in the health and social impact of the Project in terms of economical systemic gains.

Table 1. Relationship with other ValueCare Deliverables

1 The importance of engaging end-users from the outset

Patient engagement is widely accepted as the cornerstone for improving quality of care services and is a frequently stated goal for healthcare organizations.[1]

In the past, engagement has tended to focus on the relationship between patients and providers and how to improve patients' health. It is now recognised that patients need to be involved in all phases of care.

The literature shows there is not a conclusive view on how to best engage end-users. Bombard and colleagues in 2018 conducted a systematic review about the strategies for actively engaging patients and families in improving or redesigning health care and the contextual factors that influence the outcomes.[2]

According to the authors, there are different techniques that contribute to an optimal patient engagement:

- Firstly, it is important to highlight the objectives, the roles and the expectations for the patients.
- Secondly, for an optimal engagement it would be better that the target has a diversity of representation.
- Thirdly, for enhancing the engagement it is necessary to use flexible approaches, such as reports, group discussions and questionnaires.
- Fourth, it is important to give the same importance to each stakeholder or provider, using deliberation and democratic dialogue, values and beliefs exercise.
- Finally, the actions of the leader have a big impact in the engagement, because when the expert recognises the importance and the value of the patients, these ones grow their empowerment.

In conclusion according to Bombard et al, appropriate engagement is needed to achieve the programme's objectives, but they recognise this takes time. It is important to sensitise patients and families about the benefits, because on one hand they can feel empowered but on the other hand an optimal engagement requires time and energy and not all want this responsibility.

1.1 The continuum of engagement

The figure below describes a continuum of engagement (consultation, involvement or partnership) across three different levels direct care, organizational design and governance and policy making.

[1] Y. BOMBARD et al., *Engaging patients to improve quality of care: a systematic review.* https://doi.org/10.1186/s13012-018-0784-z, 2018, p.2

[2] Ibidem

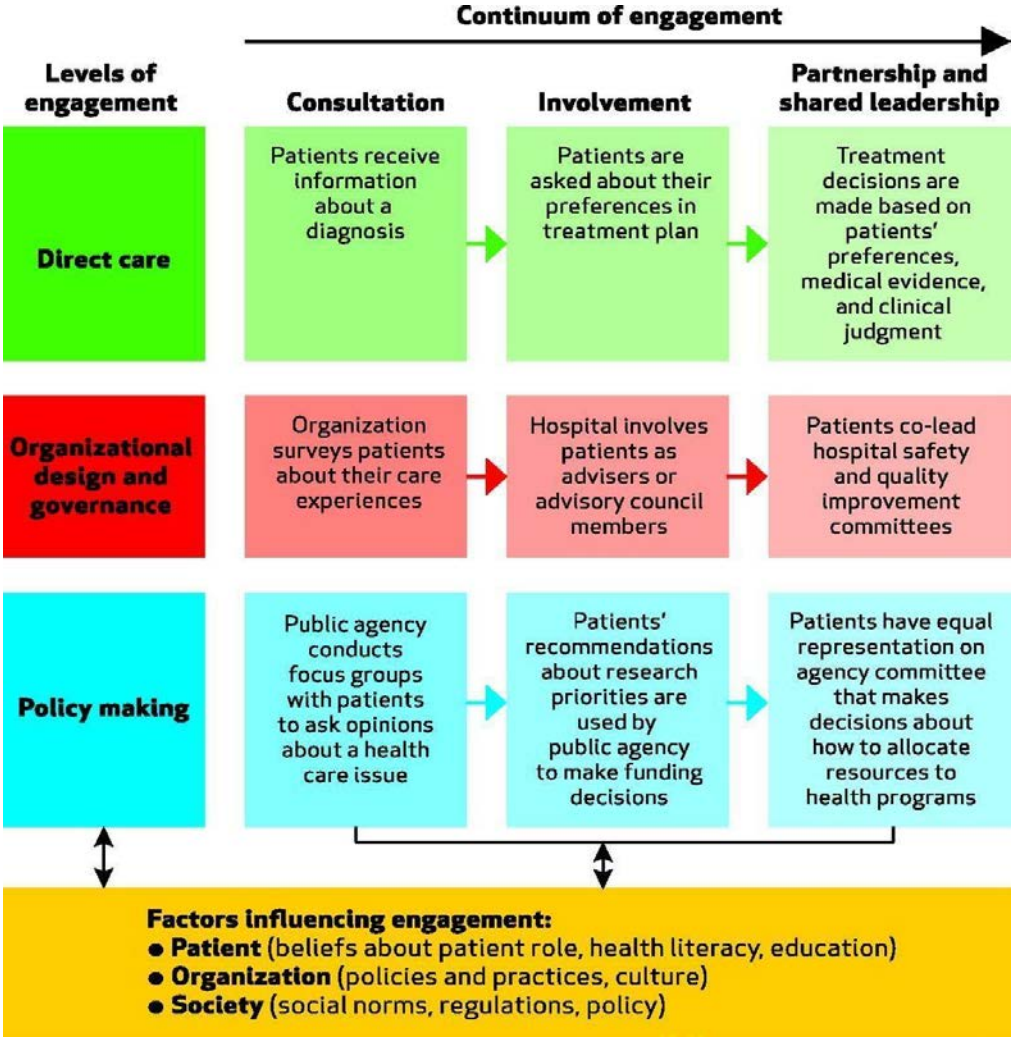


Figure 1. The engagement framework

It is important to highlight that it is not necessary to always achieve maximum engagement, because not all the patients want this responsibility. Indeed, there are some factors that influence the engagement, such as patient, organization and society. They are not exhaustive and each one can act alone or with the others. This framework was developed in conjunction with patient and family representatives, reflecting the principle of working with, rather than doing "to" or "for" patients. [3]

In the ValueCare project it will be essential to engage all end-users of digitally-enabled integrated care also considering what the main barriers to digital transformation in care are, so that these can be managed from the outset.

[3] K. L. CARMAN et al., *Patient and family engagement: a framework for understanding the elements and developing interventions and policies*. Doi: 10.1377/hlthaff.2012.1133, Health affairs 32,NO. 2 (2013), p.224

1.2 Barriers to digital transformation of care

Many promising technological innovations in health and social care end up not being adopted or scaled up. It is notoriously difficult to sustain innovation long term at the organization or system levels[4].

The problem is often that technological innovations require major transformation inside organizations. For example, in Norway 75% of the hospitals could potentially benefit from telehealth- that is health care provided remotely in the patient's home. Yet currently less than 1% of hospitals use this type of service[5].

Technologies create new opportunities, but they also break existing practices and care pathways, so when any innovation is introduced, it is necessary to consider the 'resilience' of organisations. Indeed, technological innovations can automatize certain tasks and improve security, but they can also decrease the dialogue between experts and patients.

Greenhalgh and colleagues (2017) have studied the diffusion of innovations and note that there is no single factor that stops their implementation and spread, but rather point to a dynamic interaction influencing this process.

Often initiatives the seek to implement or scale technological innovations do not consider that 'value' means different things to different stakeholders. From the patient's perspective, there was a trade-off between the potential benefits of technologies, their costs (and the person's willingness and ability to contribute to these), the work required to use them (and the person's capacity to do so), and the desirability of medicalization and surveillance [6].

Another important point could be the medical's resistance about the new technologies. Some authors presented a model with 4 elements that explained this process: resistance to policy (e.g., a policy of shifting the work of disease management from professional to patient), resistance to the sociomaterial constraints (e.g. dependability), resistance to compromised professional practice (e.g. less scope for exercising judgment) and resistance to compromised professional relationships (e.g., a perception that a remote interaction is less professional than a face-to-face one).

As for the technological approval by the patients, it seemed that there were four influences on whether an individual will engage with a health technology: motivation, personal life and values, the quality of health technology and the engagement approach.

Based on this literature review work, Greenhalgh and colleagues developed a new framework: the **NASSS (Non adoption Abandonment Scale-up Spread Sustainability)**. [7]The framework includes 13 questions in 6 sectors: the condition, the technology, the value proposition, the adopter system (staff, patient, and lay caregiver[s]), the health or care organization(s) (including attention to the work of

[4] T. GREENHALGH et al., *Beyond adoption: a new framework for theorizing and evaluating no adoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies*, Journal of Medical Internet Research 19 (11), doi: 10.2196/jmir.8775, 2017, p.2

[5] Ivi, p. 2

[6] Ivi, p.7

[7] Ivi, p. 10

implementation and adaptation), and the wider (institutional and societal) context. It also includes a seventh domain that considers interactions and adaptations over time. The framework is intended to be used reflexively to guide conversations and help generate ideas, not as a checklist [8].

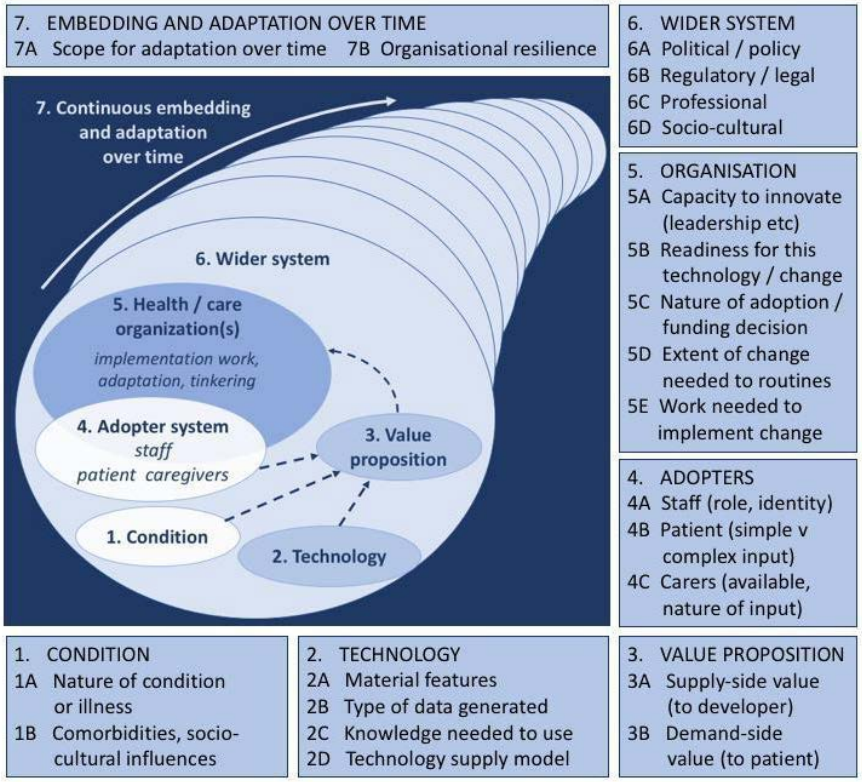


Figure 2. The new framework: NASSS

The authors suggest using the NASSS framework in the early stages of any programme because it is better to pay attention, on the care recipients' needs and from these, in a second moment develop the technology.

Implementing new technologies as part of health and social care services transformation is inherently challenging. While policy makers are calling for technology to be implemented rapidly and at scale, the reality is that when dealing with the multiple complexities of health and care, it is extremely difficult to go beyond small-scale demonstration projects.[9]

[8] Ivi, p. 10

[9] Ivi, p. 15

2 Value-based methodology for integrated care

According to Carman and colleagues (2013) patient engagement is synonymous with patient activation and patient and family-centred care. Patients, families, their representatives, and health professionals work in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care. [10] This is a corner stone of value-based health care (VBHC). In VBHC the central premise is that health and care systems must create value for patients – meaning the outcomes that matter to patients and their families. To do this, the pre requisite is engaging and empowering patients and their families from the outset and throughout all phases of care. .

There is no agreed shared definition of VBHC among the major scholars in the field. In 2017 a work in England, Wales, Italy and Scotland led to the concept of VBHC with three new distinctive aspects: personal value, allocative or demographic value and technical value.

The approach adopted is called the "Triple Value" Model:

- **Personal value**, which means that an individual receives adequate care and is determined by how the outcome relates to the value and goals of individual patients, considering both good and bad outcomes.
- **Allocative value**, determined by how fairly resources are distributed to different subgroups of the population, e.g. to people with different diseases, such as cancer or mental illness, or to groups defined by socio-demographic characteristics.
- **Technical value or utilisation value**, relative to the achievement of the best results with the available resources and determined by how the resources allocated to investment for a particular subgroup of the population, defined by their condition, are used for all the people in need in the population.

Following that, it has been suggested to add a fourth dimension to create a "Quadruple Value" Model:

- **Societal Value**, relating to whether the impact of the intervention in healthcare contributes to social cohesion, based on participation, solidarity, mutual respect, equity and recognition of diversity.[11]

[10] K. L. CARMAN et al., *Patient and family engagement: a framework for understanding the elements and developing interventions and policies*. Doi: 10.1377/hlthaff.2012.1133, Health affairs 32,NO. 2 (2013), p. 224

[11] EUROPEAN COMMISSION, *Defining Value in "Value based healthcare"*, Luxembourg: Publications Office of the European Union, 2019, p. 27-28

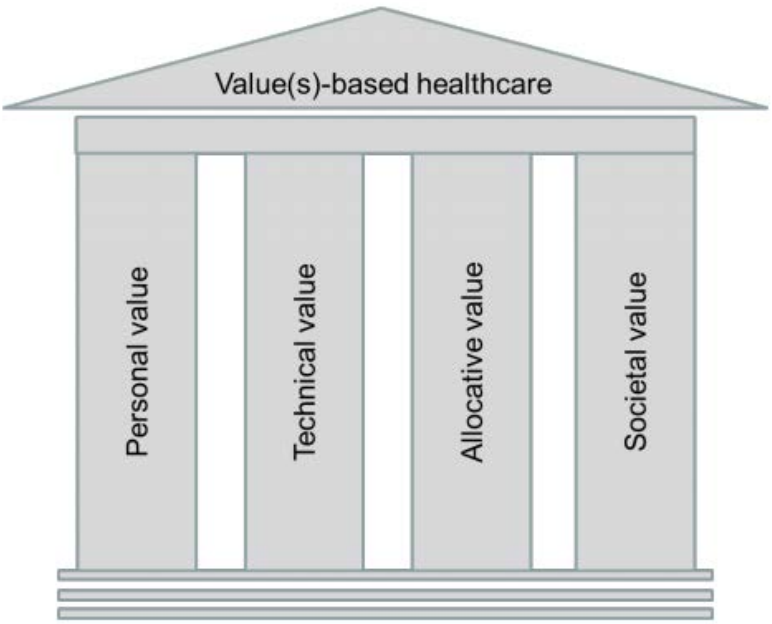


Figure 3. The four pillars for value-based healthcare in Europe[12]

[12] Ivi, p. 69

3 The pilot's description

ValueCare will be implemented in 7 large scale pilots, that have been chosen by the following considerations:

1. Geographical coverage
2. Different healthcare systems and solidarity models
3. Type of disease

The table below provides a brief description of each pilot site, their context and target population.

Pilot	National Welfare System	Target
Croatia(Rijeka)	Mostly public financing - Social Health Insurance (mixed Bismarck)	Older citizens that had a heart attack and rehabilitation
Greece (Athens)	Public health system based on Beverige model	Frail older people with neurological problems
Ireland(Cork/Kerry)	Public-private mix in financing and providing healthcare	Older people (75+) with mild to moderate frailty
Italy (Treviso)	Public and universal welfare system	Older people with diabetes or cardiovascular diseases or mild cognitive impairment
The Netherlands (Rotterdam)	Public-private mix in financing and providing healthcare, closely related to the Enthovens' model of managed competition[13][1].	Stroke
Portugal (Coimbra)	Public and universal welfare system	No or mild cognitive impairment with comorbidities and lack of social and family support
Spain (Valencia)	Public and universal welfare system	Older citizens with mild to moderate frailty

Table 2. The pilot's description

[13][1] M. KRONEMAN et al., *Health Systems in Transition*, Netherlands Health system review. *18*(2), 2016.

4 The target's description

The project has multiple and different targets:

- Older people
- Informal caregivers
- Health and social care-community practitioners, professionals and managers/ICT experts
- Public and private decision makers
- Local (in pilot sites) stakeholders/ decision makers
- European stakeholders

A deeper description of each target is presented in the following boxes.

OLDER PEOPLE

NUMBERS: 120 (intervention group)

120 (control group)

DESCRIPTION: Older people> 65 years old suffering from frailty, mild cognitive impairment, diabetes, cardiovascular diseases, neurological problems, stroke and heart attack. Every pilot site has a different target according to previous research, infrastructure available and the services offered by the country.

INFORMAL CAREGIVERS

NUMBERS:50-70

DESCRIPTION: Informal caregivers have a central role, in particular with the co-creation of the functionality and usability of the ValueCare digital solution whose design will be driven by their needs together with the other targets' needs. The digital solution will enable the informal caregiver to both monitor the care recipient while being away, and to efficiently manage emergency situations if these occur.

HEALTH AND SOCIAL CARE-COMMUNITY PRACTITIONERS, PROFESSIONALS AND MANAGERS/ICT EXPERTS

NUMBERS: 30-40 health and social care-community practitioners

5-10 organizational managers/IT experts

DESCRIPTION: This target have an important role in the transition from an outcome-based care to a value and social based care. Indeed, according to NEJM Catalyst (2017) value-based integrated care improves the satisfaction and valorisation of patients and enhances the efficiency of care through the integration of all necessary information, centralised, by also raising the motivation of professionals providing care. General Practitioners (GPs) as the main starting point of a patient journey, health and social care-community professionals as geriatricians, nurses, educators and health workers in general and ICT technicians will be involved in the co-design process for the creation of a ValueCare's digital solutions.

PUBLIC AND PRIVATE DECISION MAKERS

NUMBERS: As much as possible

DESCRIPTION: Procurers, both public and private such as public health authorities, private hospitals, large insurance companies, depending on the organisational model of the different health and social care systems, engaged at an early stage in the process of co-design and co-creation of the health and care solutions supported by ICT in order to have the opportunity of clearly sharing the needs they are expected to face at system level and better plan their investments.

The involvement of decision-making bodies in the early stage of the project has the aim of raising the impact of the intervention in the long-term and will contribute to the sustainability of the project's results and their maintenance for adoption within each ValueCare pilot site. It will also boost the potential of scaling-up results in different territories and additional fields of application promoting the project's outcome through the partners' networks and "network of networks".

LOCAL (IN PILOT SITES) STAKEHOLDERS

NUMBERS: The most important for the project's aim

DESCRIPTION: In a community-based engagement approach, the starting point is listening to local stakeholders. At various moments in the process higher levels are being explored which can influence the feasibility of solutions, such as financial systems or policy issues.

Before the beginning of the implementation, and the co-design phase, the pilot sites will engage them for signing a "*Local Alliance Agreement*" to support the local communication among the different social and health players and allow a stronger cooperation about how it would be possible to intercept and support the target population (with specific related disease in each Pilot) bringing value and gain from a new VBHC approach.

To make these Local Alliance efficient, pilot sites need to organise an initial training and seminars that will allow social and health care workers to know what VBHC Models are about, improving their awareness and sensitivity around how they could work in another way more efficient and able to determine a perceived "value" from the citizens viewpoint. These initiatives are also targeted towards volunteers, informal caregivers aimed to improve their motivational level needed to join a Pilot experience and to use the ICT solutions that will be deployed.

EUROPEAN STAKEHOLDERS

NUMBERS: The most important for the project's aim

DESCRIPTION: Engagement of the stakeholders on the European level is crucial for the increased visibility, support to the project and sustainability of the ValueCare solution after the project end. In addition, the stakeholders from the business sector should be engaged – for exploitation and commercialisation of the results (as explained further in the Work Package 7). ValueCare Project learning and lessons providing knowledge for the public health care system and for all the public and private social and health care providers belonging to the integrated care that could be deployed.

In each pilot site the Stakeholder identification will follow the social-ecological model and its adaptations. This will help to understand factors affecting behaviour and also provide guidance for developing successful programs through social environments. Social ecological models emphasize multiple levels of influence (such as individual, interpersonal, organizational, community and public policy) and the idea that behaviours both shape and are shaped by the social environment. The principles of social ecological models are consistent with social cognitive theory concepts which

suggest that creating an environment conducive to change is important to making it easier to adopt healthy behaviours.[14]

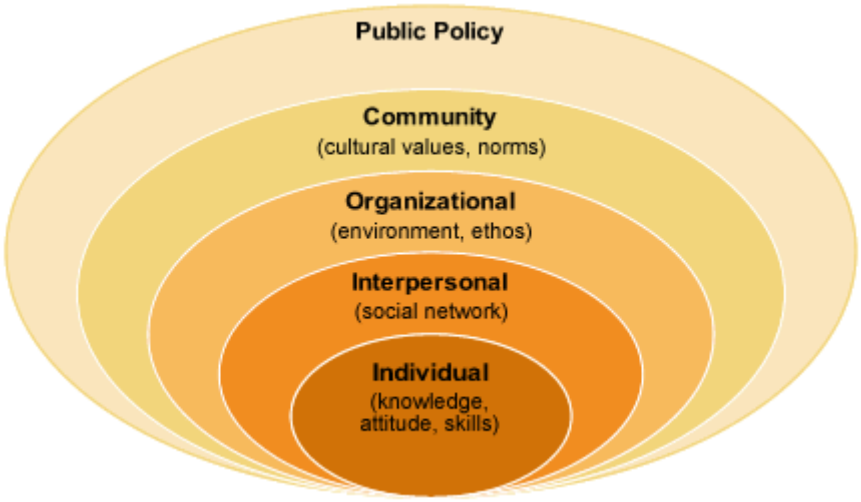


Figure 4. Social ecological model[15]

[14] http://www.esourceresearch.org/Default.aspx?TabId=736

[15] http://www.esourceresearch.org/Default.aspx?TabId=736

5 Methodology for engaging target groups

The ValueCare project considers engagement to be a process that develops as a continuum in which different actors participate and identify their strengths and their health and social needs where co-design is the ultimate aim illustrated in the figure below:

Figure 5. Continuum of Engagement[16]

The methodology illustrated in the following pages should be adapted by the local pilot's teams considering the different targets and the different context, in order to create the most functional setting to deploy the co-design actions.

The approach used in the ValueCare project for defining in parallel the value-based model and the digital solution towards an integrated person-centred care, is the co-design with end-users (older people and their families, health and social professionals and managers) and stakeholders. The aim is to 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 and requirements 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 as well.

Guidance to implement specific co-design activities are being developed alongside this strategic report and will be made available to ValueCare Project website The aim is to support pilot sites to identify and carry out the most appropriate co-design activities according to their target groups and existing resources.

The key to engaging participants to be present and interact in co-design activities is to let them be curious about what they expect, make them reflect about the critical points. This is the link between engagement and co-design: most of the time engagement means to propose some co-creative activities to future participants and already work with them in a practical way. If participants have a taste of the topic they will discuss and it will be easier to engage in the participatory activities.

The approach suggested here is aimed to create the right mindset in each target group and mainly in the care recipients. In this sense, some preparatory actions to be performed before the co-design activities, as detailed in the ValueCAre approach, are:

- Protocol to develop the co-design activities according to the target population (the D.2.6);

[16] Y. BOMBARD et al., *Engaging patients to improve quality of care: a systematic review.* https://doi.org/10.1186/s13012-018-0784-z, 2018, p.2

- Pilot site coordinator will accompany the formal/informal caregivers for 2 months to better understand their routines and hence comprehend the key functionalities of the ValueCare solution;
- A general framework and corresponding documents on ethics and data protection to guarantee that the ethical and data issues are respected in all pilot sites (related with the WP 8).

In addition to the above preparatory actions, some activities can also help pilot sites in the engagement of participants for the co-design phases, which could be adapted to the different targets:

1. Create some public events (such as fairs or public meetings) for the specific targets with an attractive theme (ex. health event in public places for screenings or questionnaires on self-management of health)
2. Create a digital survey to send to the mailing list to have a taste of the need and more interest theme to bring during the co-design activities
3. Organize generative session with the targets "to let people construct a view on the context" and give them the opportunity to understand what matter for them in a concrete and practical way starting from their day to day experiences and relationships with social and health services.
4. *Apply context mapping* [17]combined with all stakeholders in one larger graph. In this case, the context maps describe contextual characteristics of each important stakeholder. Subsequently, key complementary characteristics between stakeholders (e.g. needs in one stakeholder and resources in another stakeholder) are connected. Conflicting characteristics (e.g. conflicting needs within a single stakeholder) are also connected. *This resulted in a range of opportunities to enhance value relationships between stakeholders, and to mitigate conflicts between and within stakeholders*.

Making some co-creative activity in an early engagement phase is important to create a fast service prototype, developing the mock-up of a single touchpoint or staging the entire experience, depending on the opportunities emerging from time to time. The purpose is to attract people to the events, generating interest and curiosity to get them in the mood for co-designing, to share a common understanding about the object of conversation and lead the dialogue for the time of the activity, to collect qualitative and quantitative data in order to share, analyse and reflect on them.

The little co-design activities formats performed during the engagement phase have the effect of establishing contact with citizens: this is the first stage of connection, in which people are informed about new possibilities of doing things and of benefiting from services. The sessions will be brief, with one theme, only one meeting perhaps with longer conversation on their health status but they could be perceived as independent and effective, achieving the result of a first engagement in a bigger process of change[18].

[17]STAKEHOLDER INFORMATION MANAGEMENT SOFTWARE, *Communication strategy for stakeholder engagement,* <https://www.sustainet.com/communication-strategy-for-stakeholder-engagement/>, 2019 March 12

[18] Daria CANTU-Daniela SELLONI, *From engaging to empowering people: A set of co-design experiments with a service design perspective*. Social Frontiers, p.13

5.1 Impact of engaging patients on organizations and the care system

The power of patient's engagement consists in changing the culture of staff and care settings. The experiences reported in many articles, included shifts in organizational culture promoting further patient participation in service design and delivery [19] [20] [21], achieving collaboration and mutual learning [22] [23] [24] [25],and sharing or neutralizing power among patients and providers or staff,[26] as well as developing new competencies and negotiating for service changes [27] [28]. Interestingly, these outcomes tended to arise in mental health settings and from co-design engagements. Further analysis of the methods used in these studies revealed key enabling factors including creating deliberative spaces to share experiences, including external facilitation; broadening power and control to include users, values, and beliefs exercises; conducting user/staff/provider training; and implementing a top-down approach from the local authority.

Giving value to what counts for people and connecting services around people is the most valuable aim that ValueCare can reach with its implementation.

5.2 Engagement activities

The basic idea of engagement is to remember in any steps that the main challenge is that health and social care becomes "in reality" a dialogue, a conversation focusing on "**what matters for the patient**" rather than "what is the matter with the patient". People's involvement in health professionals' education is crucial. Some relevant works have examined the role of patients and their representative organizations in health system transformation, contributing to go a step beyond "patient-centred" care which tends to be defined by other stakeholders than patients, towards an unequivocal commitment to patient empowerment.

An important assumption is that people want to participate as "**agents**" because of their intrinsic motivation and because they feel they can contribute actively working on and for what is of value for

[19] M. BARNES & WISTOW G. *Achieving a strategy for user involvement in community care*. Health Social Care. 1994;2:347–56

[20] J. LORD et al. *Analysis of change within a mental health organization: a participatory process.* Psychiatr Rehabil J. 1994;21(4):327–39

[21] D. BARNES, J. CARPENTER, D. BAILEY. *Partnerships with service users in interprofessional education for community mental health: a case study*. J Interprof Care. 2000;14(2):189–200.

[22] S.L FRAZIER et. al., *Can't have one without the other: mental health providers and community parents reducing barriers to services for families in urban poverty.* J Community Psychol. 2007;35(4):435–46.

[23] S. TODD et. al., *Strategic planning and progress under the All Wales Strategy: reflecting the perceptions of stakeholders*. J Intellect Disabil Res. 2000;44(Pt 1):31–44.

[24] D.S BUCK et. al., *Involving homeless persons in the leadership of a health care organization.* Qual Health Res. 2004;14(4):513–25.

[25] T. MENDENHALL et. al., *The Family Education Diabetes Series (FEDS): community-based participatory research with a midwestern American Indian community.* Nurs Inq. 2010;17(4):359–72.

[26] C. HOPKINS, S. NIEMIEC. *The development of an evaluation questionnaire for the Newcastle Crisis Assessment and Home Treatment Service: finding a way to include the voices of service users.* J Psychiatr Ment Health Nurs. 2006;13(1):40–7.

[27] R. IEDEMA et. al., *Codesigning as a discursive practice in emergency health services: the architecture of deliberation.* J Appl Behav Sci. 2010;46(1):73–91.

[28] D. PILGRIM, L. WALDRON. *User involvement in mental health service development: how far can it go?* J Ment Health. 1998;7(1):95–104.

them. When an engagement pathway is organized, it is always important to keep in mind these two aspects.

After the preliminary study of the problem, evaluating the proposition and targeting the audience, the next step is about which co-creators to involve. The actions to involve the co-creator are different based on the type of target. Not all the beneficiaries connected to the objectives may benefit from a service and they may not become final users themselves. For example, they may lack digital skills or financial resources so, in order to involve a representative group of participants, it is important to understand the different way people can benefit from the services, respecting their life situation and giving values to their abilities and actions to help in co-creating. Besides, organizations and stakeholders as practitioners, are also the main participants that may contribute to social and health innovations, and should be considered the focus of co-creation, since they provide support to the target audience.

The figure below maps out a practical engagement pathway.

Figure 6. Engagement pathway for ValueCare project

5.2.1 Key questions

KEEP IN MIND...

What is the purpose of engagement activity?

What are you trying to get out of this activity?

How do you define success?

Is this activity necessary in generating and sustaining the social innovation being developed?

What are your key objectives?

why is engagement critical to fulfilling these?

Who do you want to engage?

What are the barriers to participation?

How can people be incentivised to participate?

What are the dynamics of the groups of citizens you want to work with?

Can you tolerate uncertainty of outcomes?

Who is best placed to deliver this project or approach?

Do you have the resources to make engagement effective?

Can you manage stakeholders' expectations effectively?

6 Engagement toolkit

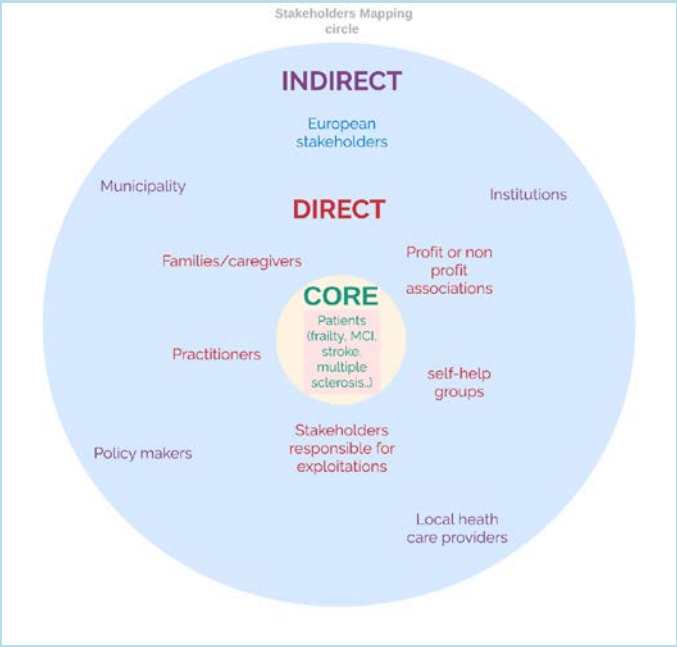
1. IDENTIFY SIGNIFICANT TOUCHPOINTS

- Map the already existing patient care pathway journeys in each pilot to highlight any bottlenecks faced, and the communications and information gaps
- Delineate the main touchpoints (A touchpoint is any interaction (physical or not) that might alter the way an end-user feels about the service)
- Identify the interaction types:
  - Appropriate: it means that both the context of the interaction and the cultural tone of the interaction, meet the needs of users
  - Relevant: it means that the function performed by the interaction meets the utility requirements of the users
  - Meaningful: it means that the interaction was perceived as important or purposeful by the users
  - Endearing: it means that the interaction created some form of bond with the users
- Ask to practitioners to give their viewpoint about the patient journey now and which might be the improvement that could be done to create "value" along the care chain and among services dynamics
- Use the attached form for local implementation actions:

Tool 1 – Attachment 1 "Identify significant patient-services touch points"

2. MAPPING STAKEHOLDERS

- List down Pilots' stakeholders
- Identify and select local opinion leaders belonging to the diseases related services, then interview them
- Survey them and learn what they think about the organization and the project
- ask who influences them (opinion leaders) and how they want to receive information from you
- Categorize the several subjects by how they impact your organization (not all have the same relevance
- Divide stakeholders in: core (the direct objective, the ones involved in the process who could be the co-designers), direct (who will benefit from the project and could have positive direct consequences from it), indirect (the ones that can support the objective of the process and that are really important for the success of it in a long term vision)and put it in a circle map as the example below:



- Determine the factors to use to rate each stakeholder
- Identify the most relevant ones
- Set up the ValueCare communication presentation
- Define a local engagement plan timeline and contents
- Monitor the process
- Ensure that everyone is modelled from the same final aim and have the same values
- Use the attached form for local implementation actions:

Tool 2 – Attachment 2 "Local Stakeholder Identification Matrix"

3. CONTACT WITH PROFESSIONALS

- Consider central caretaker as the key figure to adopt an integrated value-based health and social care model
- Map the alliance of practitioners and find the most influential and motivated ones in joining the proposal
- Include GPs, nurses, geriatricians, rehabilitation profiles and the experts in the social and health care domain
- Ask some key: do they know what Value based health care means? How is it possible to help them increase their awareness of this concept?
- Some tips to make them more comfortable and less intimidating to participate in co-design:
    - Find a way to reward them (ex. credits for their profession)
    - Always give time for each person to introduce themselves and their roles, never assume everyone knows each other
    - Always welcome new members and explain what happens at a multidisciplinary meeting and what is expected of them
    - Be aware that health and social care is a language of its own, avoid using acronyms and medicalised language, without explanation
    - Use a common person-centred language: do not forget the objectives of the project
    - The role of the conductors is crucial in maintaining a productive environment. This is a learnt skill and further training may be required
- Considering the engagement of the ICT experts, follow the actions listed below:
    - Map in each Pilot Site the existing ICT infrastructure belonging to the local health and social organizations and identify the top managers that are in charge of them
    - Invite in each Pilot Site the ICT manager at the ValueCare's events where the co-design groups will be conducted
    - Prepare the documentation (clinical and technical) that will represent the existing clinical pathways, experiences and critical touchpoints, arisen with the care recipients, relatives and practitioners' discussions
    - Set up the baseline that could be used, depending on the pilot's disease specifications, useful to create and enrich the "ontology" required by the AI and the ML that will be delivered
    - Pilots should use the attached Form for these local implementation actions:

Tool 5 – Attachment 5 "Pilot local data gathering flow mapping"

4. SOCIAL NETWORKS AND INFLUENCERS

- Involve the organizational leaders as key facilitators. Thisincludes top-down approaches and at community levels where local champions led initiatives or were actively engaged to ensure their success
- Have managers and executives recognize and advocate for the importance of patient involvement; it fosters a sense of empowerment and commitment among patients and ensured organizational sustainability of the engagement
- Leadership action has shown to help align the engagement findings or recommendations and ensure that they are advanced within the organization's relevant strategic plans and policies in primary care
- Ensure that the engagement occurs prior to decision-making, rather than providing input on proposals to which services are already committed
- Use the power of social networks to give the opportunity of making citizens committed influencers of the idea
- Have different leaders/influencers for different targets
- Interview politics, policy makers, representatives of different services to engage institutional stakeholders with direct and short videos
- Influencers must believe in VBHC, be trained and explain in some powerful tips how the system and diagnostics phase can evolve
- Define a local digital ValueCare campaign choosing the right Social channel for each specific target looking at the statistics, data related to the local context, culture, habits and people interests in health
- Use powerful communication following these tips:
    - Make sure all information regarding your project is presented in a transparent way
    - Communicate with stakeholders in the manner that works best for them
    - Do not judge what for your stakeholders has value
    - Provide feedback to stakeholders on how their interests and issues are addressed and resolved.
    - Keep a careful record of all aspects of stakeholder communications that occur over time

5. VOLUNTEERING

- Train peer-to-peer older volunteers that could be the ambassadors of ICT usage is the best answer to the question: "how to raise the curiosity of older people to participate in co-creation" especially when this means using ICT devices?"
- Be careful during the recruitment phase. We want them to be able to fit tasks around their existing commitments and adapt them to fit their lifestyle
- Have these concepts in mind:
  - What are the types of volunteers we need?
  - What information appeals to each one?
  - What could be important for them?
  - How might we engage them? Through interviews, questionnaires, workshops, events, fairs?
  - Use guided conversation to understand how motivated they are to improve and level of support is required
  - Use motivational interview to express empathy, develop opportunity for authentic discussion and support self-efficacy
- Create a volunteer role description for recruitment that should contain:
  - Role title
  - Level of commitment required
  - Supervisor
  - Role summary
  - Level of commitment
  - Area we ask to cover
  - What are the characteristic volunteer ambassadors should have (psychological attitudes)
  - Main task
  - Induction and training: assure them that they will be teached and supported
- Keep in mind these questions when manage the volunteer ambassadors:
  - Do your goals match those of the volunteer?
  - Are they meaningful to them?
  - What role do they play as part of the team?
  - What role do they play as part of the achievement of the vision and goals?
  - What matters to them?
  - How do they gain role satisfaction - Extrinsic and Intrinsic factors
  - How do you communicate the vision to your volunteers?
  - How and how often do you communicate with each other?
  - What are their communication needs? What are yours?
  - What do volunteers need to help them feel confident and competent in their role?

6. PERSONAS PROFILE

- Focus on patient narratives that describe what "good" looks like through a patient's eyes and can help in the development of appropriate measures
- Let you be guided by "I statements" such as:
  - I will tell my story once
  - I am listened to about what works for me, in my life
  - I am always kept informed about what the next steps will be
  - The professionals involved with my care talk to each other; we all work as a team
  - I always know who is coordinating my care
  - I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time
- Fill in a PERSONAS profile and identifies profiles of the main targets with similar characteristics
- Choose the PERSONAS whose experience you want to reconstruct and fill in the map-journey header. Different type-users may have different experiences using the same service
- Identify the phases in which the experience takes place by thinking about what happens before, during and after the interaction with a service
- Build the whole path by describing what actions or activities the user does in each phase and indicating the needs or critical issues emerging at each moment.
- Think about how the existing services respond to the user's needs at each stage, giving an assessment of how their mood oscillates between satisfaction and frustration.
- Pilots should use and adapt the attached Form for these local implementation actions:

Tool 3 – Attachment 3 "User Journey sheet"
Tool 4 – Attachment 4 "Personas Profiles"

7 Case study: SEFAC as an example of social engagement framework for chronic disease challenge

SEFAC[29] (Social Engagement Framework for Addressing the Chronic Disease Challenge) funded by the 3rd EU Health Programme project supports the actions in the European regions, in alignment with national/EU efforts to reduce the burden of major chronic disease and to increase the sustainability of health systems.

SEFAC fosters the involvement of volunteers in a broad community approach initiated by social and health care. The goals of the SEFAC project are development and implementation of an effective and efficient social engagement model for the prevention and self – management of major chronic diseases, promotion of healthy lifestyles, increase of empowerment among citizens, promotion of self – efficacy and adaptation of a completely new community – based intervention.

The objectives are to:

- Assess the needs of citizens with (risk for) major chronic disease (aged circa 50 years and older) for delivery of community services and support by volunteers, using a variety of methods e.g. literature review and focus groups.
- Develop an implementation plan that discusses extensively the implementation question and how to involve the stakeholders in the implementation phase of the scale up process.
- Create a training plan and a train the trainers' plan for adoption and implementation of the Social Engagement Model.
- Deliver training sessions for the Social Engagement Model (including the involvement of volunteers) in the pilot sites

All the pilots involved set up SEFAC Alliance with relevant stakeholders on pilot site level. Many conferences to explain the framework of the project have been done in all the 4 pilots involved (Rijeka, Treviso, Rotterdam, Cornwall).

Stakeholders had a crucial role by inviting and mobilizing citizens to participate in local open events to promote screening for (risks of) major chronic diseases, and to promote healthy and active lifestyles, and to exchange ideas on the role of changing harmful habits into healthy everyday practices. World cafés with possible participants and volunteers have been conducted by trained trainers (practitioners and psychologists) during the first phase of the implementation.

In collaboration with Volunteering associations, 15 volunteers per pilot were recruited. Each team pilot organized the initial meeting with volunteers that was a world café, followed by a 5 weeks training guided by the handbook *Train the trainers* with the aim to introduce volunteers with the SEFAC project. According to the before mentioned manual, learning outcomes were:

- understand the key principles of the innovative SEFAC model
- explain the goals of SEFAC Citizens Training Start from yourself - Lifestyle changing program.
- develop an understanding of the roles and responsibilities in the SEFAC project

[29] https://sefacproject.eu/

- use facilitation skills to deliver an effective training and support to participants

Main tasks of volunteers were attending the workshops, helping with the organization of the workshops, attending the public events, disseminating the project activities, supporting and encouraging the participants to change their lifestyle and to practice mindfulness. Then, through other public events and the help of the trained volunteer ambassadors 90 participants per pilot were involved in the 7 weeks workshop. The force of the alliance was that ambassadors and local stakeholders were updated with planned meetings and involved in all the initiatives in order to make them feel part of the project and they were also involved in some consultation about the pilot implementation.

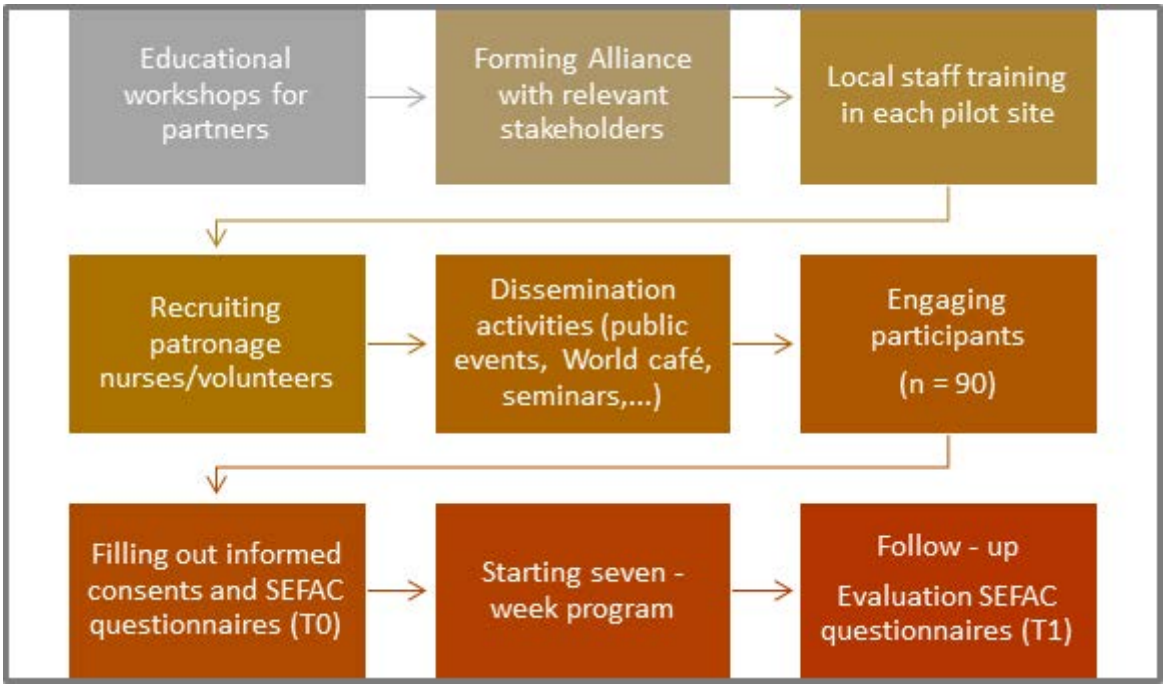


Figure 7. SEFAC project: the example of Rijeka pilot engagement and implementation

8 Risks in developing new solutions on social and health challenges for engagement

RISKS OF ENGAGEMENT...

Spread the wrong messages because of the lack of a good communication

Not being clear about the timeline and what is required to all the participants involved

Reinforce rather than weaken existing power dynamics

Self-exclusion: some might feel not adapted or that they can't or should not take part

Not include all the representative figures of a community

why is engagement critical to fulfilling these?

Adopting poorly practiced forms of engagement: It can create harm by making long term disengagement more likely

9 Target engagement timeline

The suggested timeline for engagement and co-design activites is presented in the table below. Due to the contingency situation related to the worldwide pandemic of COVID-19, the actions' implementation could be done remotely, in each Pilot site, depending on the digital literacy of the target involved and the opportunity to join the specific events in presence or on-line.

Depending on the availability of older people, informal caregivers, practitioners and ICT managers, decision makers, EU stakeholders, the proposed timeline could vary with a delay that, anyway, will consider the Work Packages and Tasks interactions.

Local marketing activity	M. 6-7 (MAY-JUN 2020)	M. 10-11 (SEP-OCT 2020)
Action progress		
1. Identify significant touchpoints	Adapt and implement the "user journey" form provided to map the existing situation	
2. Mapping stakeholders	In collaboration with local stakeholders: Creation of local networks and stakeholders (associations, caregivers associations, other local and European stakeholders)	Improvement: Creation of local networks and stakeholders (associations, caregivers associations)
3. Contact with professionals	In collaboration with local formal partners and stakeholders: creation of alliance with health and social professionals for the sensitization and the co-design activities	Improvement: creation of alliance with professionals' advocacy to elicitate the participations of social and health care sector
4. Choose the right Social Network and influencers	In collaboration with local formal partners : Exploring and mapping the main social activities (creation of guidelines on how to use them with older people) in accord to the WP8	Improvement: Exploring and mapping the main social activities (creation of guidelines on how to use them with older people) in accord to the WP9
5. Volunteering	In collaboration with local formal partners: identify and train volunteers as ambassadors for the local dissemination actions towards citizens	Improvement - train volunteers as ambassadors for the local dissemination actions towards citizens

6. Personas Profiles	In collaboration with local formal partners: adapters Personas profile of targets needed using approved models from literature as Personas (https://ec.europa.eu/eip/ageing/news/12-personas-have-been-developed-enable-eip-aha-envision-realistic-health-and-care-needs-certain_en) for three different targets	Improvement: identify the profile of targets needed using approved models from literature as Personas (https://ec.europa.eu/eip/ageing/news/12-personas-have-been-developed-enable-eip-aha-envision-realistic-health-and-care-needs-certain_en) for three different targets
7. Public events for co-design	Organization of events to present ValueCare Project, main future steps and recruitments for the codesign activities	Plan next events to present ValueCare Project, main future steps and recruitments for the codesign activities

Table 3. Target engagement timelines

10 Conclusion and future work

This deliverable is elaborated to provide a methodology to engage the target groups in ValueCare project. The target groups in multiple and consists in:

1. Older people
2. Informal caregivers
3. Health and social care-community practitioners, professionals and managers/ICT experts
4. Public and private decision makers
5. Local (in pilot sites) stakeholders/ decision makers
6. European stakeholders

This version suggests guidelines that will lead the way to the engagement preparation but it will be necessary to gather all the local feedback that the stakeholders, the local community and the main targets will give to the local Project's team members.

The guidelines are the results of an adaptation of Anglo-Saxon literature review. This could be a limitation since the geographic position of the partners covers also Mediterranean area. These obstacles could be exceed thanks to the pilot adaptation during the implementation phase that will fill up the differences between geographic areas and the gap among them.

Furthermore, the D2.3 is strongly connected to the D2.4 about the co-design methodologies that should be deployed once that the Project's target has been reached out and engaged into the local public events. In such a way there is a dynamic relationship between those deliverables that should be matched during the next months based on the timeline of the WP's implementation and the related tasks actions.

Attachements

Tool 1 – Attachment 1 "Identify significant patient-services touch points"

	What happened/Description of the problem?	Who is the first service/person I call on?	Where do I phisically go? (ex. Hospital, surgery etc..)	How do you consider the path (easy, clear etc.)?	How much time does it take?
Older people					
Caregivers					

Tool 2 – Attachment 2 "Local Stakeholder Identification Matrix"

Kind of services	Name 1	Name 2	Name 3	Name 4	Name 5
Hospital	please tick if the organizations provide it				
Home care provider					
Housing provider					
Daily center					
Insurance Companies					
Rehabilitations services					
Other to be added locally					

Tool 3 - Attachment 3 "User Journey Sheet"

User Journey: Describe the citizen's experience in interacting with a service

INSTRUCTIONS

- Choose a **role** or **user-type** (personas) whose experience you want to reconstruct and fill in the map header. Different type-users could have different experiences using the same service.
- **Identify** the phases in which the experience takes place by thinking about what happens **before, during and after** the interaction with a service. Arrange the phases in a linear logical sequence along the horizontal axis, **adding or removing columns** depending on the number of phases identified.
- Build the entire path by describing what **actions or activities** the user performs in each phase and indicating the **needs or critical issues** emerging at each time.
- Finally, think about how the existing services respond to the user's needs at each stage, **giving an assessment of how their mood** oscillates between satisfaction and frustration.

Repeat the same process for each user-type

Name, Age, Disease (ex. Stroke)

PHASES	BEFORE RECEIVING CARE				RECEIVES CARE							AFTER CARE
Older customer journey	Reads news and creates opinion	Need for care arises	Continues life with need unmet	Trigger: Something sudden happens that forces action	Acute care at hospital	Information dump: Care plans, coordination meetings, local government team	Makes choice of care provider	Starting up care in the home, setting up a plan with home care staff	Isolated in my home	Moves to an elderly care home	Stay in elderly care and passes away	

Name, Age

PHASES	BEFORE RECEIVING CARE				RECEIVES CARE						AFTER CARE
Informal caregiver			Points out need and suggests getting help			Present at care plan meeting. Mental support for the elderly.	Takes part in decision process. Mental support for the elderly		Provides psychological support and quality control of the care the elderly receives	Main decision maker, elderly no longer as capable.		Grief, Termination and wrap up of care and services

Tool 4 - Attachment 4 "Persona Profiles" Patient

BLUEPRINT
DIGITAL TRANSFORMATION OF HEALTHCARE FOR THE AGEING SOCIETY

Web: https://ec.europa.eu/eip/ageing/blueprint_en
Contact: WE4AHA@empirica.com

Meet Eleni

Name: Eleni **Country:** Greece
Age: 73 **Area:** urban
Life course: retired person
Need: chronic conditions and social needs
Connectivity: broadband, smart phone

Internet usage	Low	High
Mobile device skills	Low	High
Affinity to new tech	Low	High
Digital Health Literacy	Low	High
Assistance (ICT use)	No	Yes

Eleni is a retired civil servant, divorced, and lives alone in an urban area with no family living nearby. Recently, to her frustration, she has been having episodes of memory loss (early stage dementia) and her energy levels have been dropping. She is also under treatment for high blood pressure. She is currently being monitored by her doctor and by the staff in the nearest municipal elderly care facility. She also has regular check-ups with a hospital neurologist. Eleni follows a home-based programme of cognitive and physical activities because services from a Dementia Day Centre are not available in her town. Eleni also tends to forget her medication and she is worried about having other accidents due to her dementia.

What's important to Eleni

- ✓ Being active and able to support herself independently.
- ✓ Reducing the burden of her chronic disease management.
- ✓ Spending time with her friends.
- ✓ Feeling safe at home while dealing with her condition.

Daily living

- ✓ Her early stage dementia makes adherence to medication and following a healthy lifestyle challenging.
- ✓ She follows a programme of cognitive and physical activities alone at home, since the closest Dementia Day Centre is based in another (bigger) city.

Own resources & assets / support

- ✓ High level of education.
- ✓ Friends at the local municipal elderly centre.
- ✓ Medicals costs are covered by the national health system.
- ✓ Visits 2x /week from the Greek public home care service system (a service for elderly with social care needs).

Events, issues & personal concerns

- ✓ Feels stressed with the everyday challenges of dementia.
- ✓ Worried about having accidents at home.
- ✓ Has social needs since no family members live nearby.

Health concerns

- ✓ High blood pressure.
- ✓ Dementia.
- ✓ Adherence to treatment and memory exercises is challenging.

Health tests

- ✓ Check-ups with GP and e-prescription every 1-3 months.
- ✓ Regular follow-up and clinical assessments from neurologist.
- ✓ Annual or bi-annual laboratory tests.
- ✓ Blood pressure checks and physical examinations.
- ✓ Dementia stage re-evaluations.

Treatment: medications, therapies, etc.

- ✓ 1 pill for high blood pressure.
- ✓ 1 pill for dementia.
- ✓ 1 patch for dementia.

Care professional concerns

- ✓ She sometimes misses some check-ups and appointments with her doctor (due to her dementia).
- ✓ Adherence to treatment is difficult due to memory loss.

Unmet needs

(1) Eleni wants to benefit from services typically offered in a Dementia Day Centre, but such services (e.g. memory exercises, patient empowerment programmes) are only available in bigger cities.
(2) Eleni does not fully benefit from her local hospital care services due to occasional memory loss and lack of family support.
(3) Eleni's adherence to her treatment is not optimal due to her dementia.
(4) Eleni is worried about her safety (e.g. having accidents, fires, falls) since she lives alone with early stage dementia.
(5) Eleni may need support in planning for the future such as moving closer to her family or to an area close to a Dementia Day Centre so that her health and condition are better managed especially as her dementia progresses.

This persona was developed by George Dafoulas, eTrikala with the kind support of the WE4AHA Blueprint and expert team.

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Tool 4 - Attachment 4 "Personas Profiles" Informal caregiver

BLUEPRINT
DIGITAL TRANSFORMATION OF HEALTHCARE FOR THE AGEING SOCIETY

Web: https://ec.europa.eu/eip/ageing/blueprint_en
Contact: WE4AHA@empirica.com

Meet Leila

Name: Leila **Country:** UK
Age: 51 **Area:** residential (rural)
Life course: working adult
Need: generally well / good wellbeing
Connectivity: broadband, smart phone

Internet usage	Low	High
Mobile device skills	Low	High
Affinity to new tech	Low	High
Digital Health Literacy	Low	High
Assistance (ICT use)	No	Yes

Leila is in good health and works as manager in a senior home. She lives in a small village, 13 km from the nearest city, together with her sons, Sammy (10) who has type 1 diabetes and Ed (20), as well as Ed's girlfriend. Leila is sporty and active and does not experience any special difficulties going through menopause, but her divorce 4 years ago has complicated her life. She also provides moderate support as an informal carer to 3 elderly adults in her life: her father, who lives in a different town; her ex-mother-in-law, who has dementia and lives in a care home, and her 93-year old neighbour, who lives alone in a bungalow.

What's important to Leila

- ✓ Staying in good health; attending a weekly Tai Chi class and running 2x/week, keeping a small garden in shape.
- ✓ Family-oriented but keen to become more independent (e.g. moving home once eldest son and girlfriend graduate).
- ✓ Being socially conscientious and people-focused.
- ✓ Being good at multi-tasking.

Daily living

- ✓ Leila balances well her multiple responsibilities.
- ✓ Leila and her family are highly dependent on her income.
- ✓ Both her job and family require her to stay healthy and mobile (able to travel).

Own resources & assets / support

- ✓ Leila remains economically independent until retirement age.
- ✓ Her 2 sons are helpful around the house and in the garden and she has a cleaner who comes twice a week.
- ✓ Leila, her son and his girlfriend are all able to drive.
- ✓ She is well-informed about the local care services on offer.

Events, issues and personal concerns

- ✓ Winters can sometimes be tough, especially because of the amount of car driving Leila does. She wonders whether she could be experiencing winter depression ("Seasonal Affective Disorder – SAD") and would like to bring this up with her GP.

Health and lifestyle concerns

- ✓ She has no immediate health concerns, but her eyesight is potentially worsening; she had occasional back problems in the past due to work that required heavy lifting.
- ✓ She had several short-term relationships in the past. On one occasion, she experienced bladder inflammation (cystitis).
- ✓ She is menopausal but experiencing no side-effects.

Health tests

- ✓ Regular breast cancer tests and cervical smears.
- ✓ Regular blood pressure tests.
- ✓ In the future when Leila turns 60, she will be able to have a general comprehensive health check/test.

Treatment: medications, therapies, etc.

- ✓ Still taking oral contraceptives, which are free with her country's health service.
- ✓ Keeps a standard "first aid kit" in the house, filled with aspirin and paracetamol just in case they are needed.

Concerns as a carer

- ✓ Leila is less concerned with the situation of her father and ex-mother-in law, but is considering getting in touch with her elderly neighbour's family about potential future care needs.
- ✓ Due to her own family responsibilities, she may overlook her own needs as an individual.

Unmet needs

(1) Food shopping service for herself and her neighbour.
(2) Potential insulin training for her son, Sammy, so that he can start monitoring his insulin himself.
(3) Information on SAD and/or potential check-up with doctor.
(4) Because Leila is a member of the Asian community, with particular health development needs, she is aware of people close to her who are developing or who are at risk of developing diabetes.
(5) Leila is aware of elderly members of her community who have language difficulties when talking about their health situations and needs.

This persona was developed by Diane Whitehouse, EHTEL and Soo Hun, Public Health Agency, Northern Ireland with the kind support of the WE4AHA Blueprint and expert team.

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Tool 5 – Attachment 5 "Pilot local data gathering flow mapping"

Kind of services	Data available and kind of record	Data available and kind of record	Data available and kind of record	Data available and kind of record	Data available and kind of record
Hospital	please tick if the organizations provide it				
Home care provider					
Housing provider					
Daily center					
Insurance Companies					
Rehabilitations services					

GPs					
Pharmacies					
Other to be added locally					

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