



## D2.1 REQUIREMENTS FOR CAREWELL INTEGRATED CARE MODELS AND PATHWAYS

### **WP2 CAPTURING AND DOCUMENTING OF USER, ORGANISATIONAL AND FINANCIAL, LEGAL AND INITIAL TECHNICAL REQUIREMENTS**

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## DOCUMENT INFORMATION

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CO	Confidential, only for members of the consortium (including the Commission Services)	

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This deliverable contains original unpublished work except where clearly indicated otherwise.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

CareWell will predominantly focus on the provision of care and support to older people who have complex health and social care needs through ICT enabled healthcare services coordination, monitoring, patients self-management and informal care givers involvement. Specifically, CareWell will pilot services at six sites across Europe based on two pathways: (1) integrated care coordination and (2) patient empowerment & home support pathways supported by ICT.

Naturally, each pilot site's services will differ according to the level of maturity of their integrating care strategies, the infrastructure already available, legacy systems, the current organisational models and the approach they take to implementing the pathways. To reflect these differences work package 2 undertakes the capturing of requirements and the subsequent drawing up of use cases. This deliverable reports on the first of these activities: requirements.

This deliverable aims to capture, collate and document requirements for the CareWell integrated care models and pathways at each pilot site to ensure that the CareWell services are fit for purpose and meet the project goals. The focus of efforts in the requirements gathering exercise has been users; specifically all relevant requirements relating to the characteristics of key CareWell user groups (older, frail people and care professionals). Ensuring that users' needs are met is essential to ensuring that the services are successful and are able to meet their intended target of supporting older people with complex care needs. As a supporting activity, to ensure that the services meet the project's goals and specifically the users' needs to the fullest feasible extent, the organisational, financial, legal and initial technical requirements, for appropriate service design and delivery have also been captured.

This deliverable describes the activities carried out for requirements gathering and the requirements captured by the pilot sites. These requirements will form a corner stone for further service development and will inform the development of use cases, organisational models and integration architecture as the CareWell project advances.



# 1 INTRODUCTION

## 1.1 INTRODUCTION TO THE PROJECT

The CareWell project will enable the delivery of integrated healthcare to frail elderly patients in a pilot setting through comprehensive multidisciplinary and tightly knit programmes. ICT will play a major role in the coordination and communication of healthcare professionals and of patient centred delivery of care at home. CareWell will predominantly focus on the provision of care and support to older people who have complex healthcare needs, are at high risk of hospital or care home admission and require a range of high-level interventions due to their frailty and multiple chronic diseases. This will be achieved through ICT enabled healthcare services coordination, monitoring, patients self-management and informal care givers involvement. The ICT platforms and communication channels will avoid duplication of effort when dealing with patients' diagnostic, therapeutic, rehabilitation or monitoring and support needs. Additionally, ICT-based platforms can improve treatment compliance, enhance self-care and self management and increase patient and carer awareness on their health status. All of which will improve clinical outcomes and enable people to lead fulfilled lives.

Moreover technologies will support the patients' informal caregivers highlighting when respite care or additional professional input is required. The two CareWell services are based on (1) integrated care coordination and (2) patient empowerment & home support pathways supported by ICT. These care pathways will cut across organisational boundaries. They will activate the most appropriate resources healthcare and social care services available, both for scheduled and unscheduled care. Information sharing will need to comply with European and national regulations relating to consent and privacy. The ICT platform will be based, whenever possible, on open standards and multi-vendor interoperability and collaboration among ICT suppliers will be strongly encouraged.

## 1.2 AIMS OF THIS DELIVERABLE

This deliverable aims to capture, collate and document requirements for the CareWell integrated care models and pathways at each pilot site. The focus of efforts in the requirements gathering exercise has been users; specifically all relevant requirements relating to the characteristics of key CareWell user groups (older, frail people and care professionals). As a supporting activity, to ensure that the needs of users are met to the fullest feasible extent, the organisational, financial, legal and initial technical requirements, further work on technical requirements will be part of the specification work in WP4, for appropriate service design and delivery have also been captured and are presented in this deliverable.

The results of the requirements gathering activities documented in this deliverable will be used to inform the development of use cases in WP2, the design of organisational models in WP3 and the drawing up of specifications in WP4. Work packages 2,3 and 4 are the design work packages and thus the first stage of the development of the CareWell services and pathways. The three design work packages will work collaboratively together and employ a process of testing and iteration to ensure that the CareWell services are fit for purpose, useable and meet the users' requirements. Please see below for illustrations of how the work packages fit together across the project.

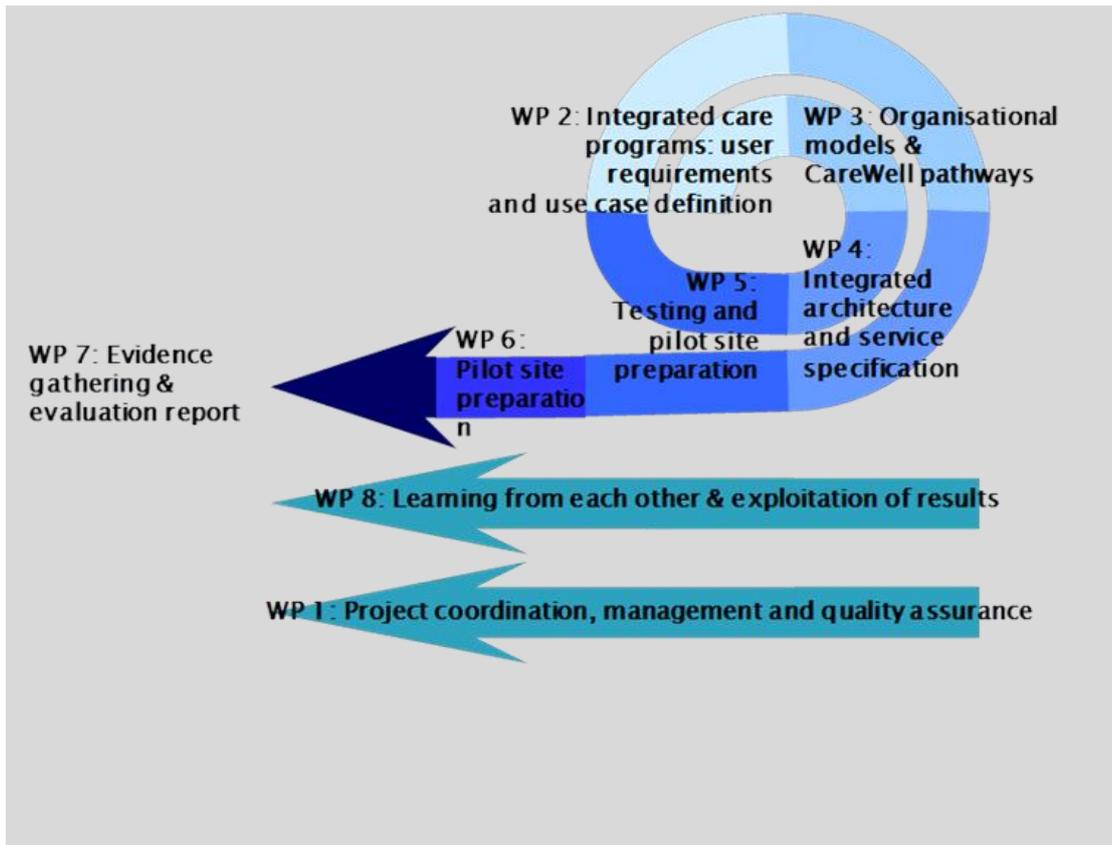


Figure 1: CareWell work package interdependencies

### 1.3 STRUCTURE OF THIS DELIVERABLE

This document is organised as follows. Chapter 2 describes the methodology undertaken for the gathering and documenting of requirements and for the inclusion of appropriate representatives. Chapter 3 then goes on to describe the service components, envisaged outcomes, impact and usage of the two CareWell pathways, integrated care coordination pathway and patient empowerment and home-support pathway, for which requirements are gathered. Chapters 4 to 8 then include the requirements which were gathered at each pilot site according to their design element's perspective; this means chapter 4 includes patient and informal carer user requirements, chapter 5 documents healthcare professional user requirements, chapter 6 describes organisational and financial requirements, chapter 7 details technical requirements and chapter 8 includes legal and regulatory requirements. Requirements for each design element were gathered, where applicable, for each of the two pathways separately and so are documented in this way. Chapter 9 then concludes this deliverable with a description of the proposed next steps for the use of these requirements in further design and development of the CareWell care models and pathways. In the Annex are the standard requirements gathering templates.

## 2 METHODOLOGY

Starting from a outline of the service components and the envisaged outcome, impact and use of the services described in chapter 3 below, and utilising the experience and knowledge gained from involvement in previous requirements gathering activities in other projects on ICT-based solutions for care integration, templates for the gathering of user requirements were designed by empirica. Each template was addressed to one of the two CareWell pathways, described in chapter 3 and a particular design element, so that there were templates for:

- Patients and informal carers- user requirements
- Healthcare professionals- user requirements
- Organisational and financial requirements
- Technical requirements
- Legal requirements

The templates also included instructions on how to populate the templates such as through the use of interviews and focus groups with relevant participants for which guidance, and in the case of patients and informal carers consent forms for participation in interviews or focus groups, were included. These templates can be found in the Annex of this document.

The templates were reviewed by Kronigune before they were shared with pilot sites. Pilot sites were requested to suggest alterations and additions to the templates in order to tailor them to their specific pilot site situation. For an overview of the steps taken for gathering requirements please see the figure below.

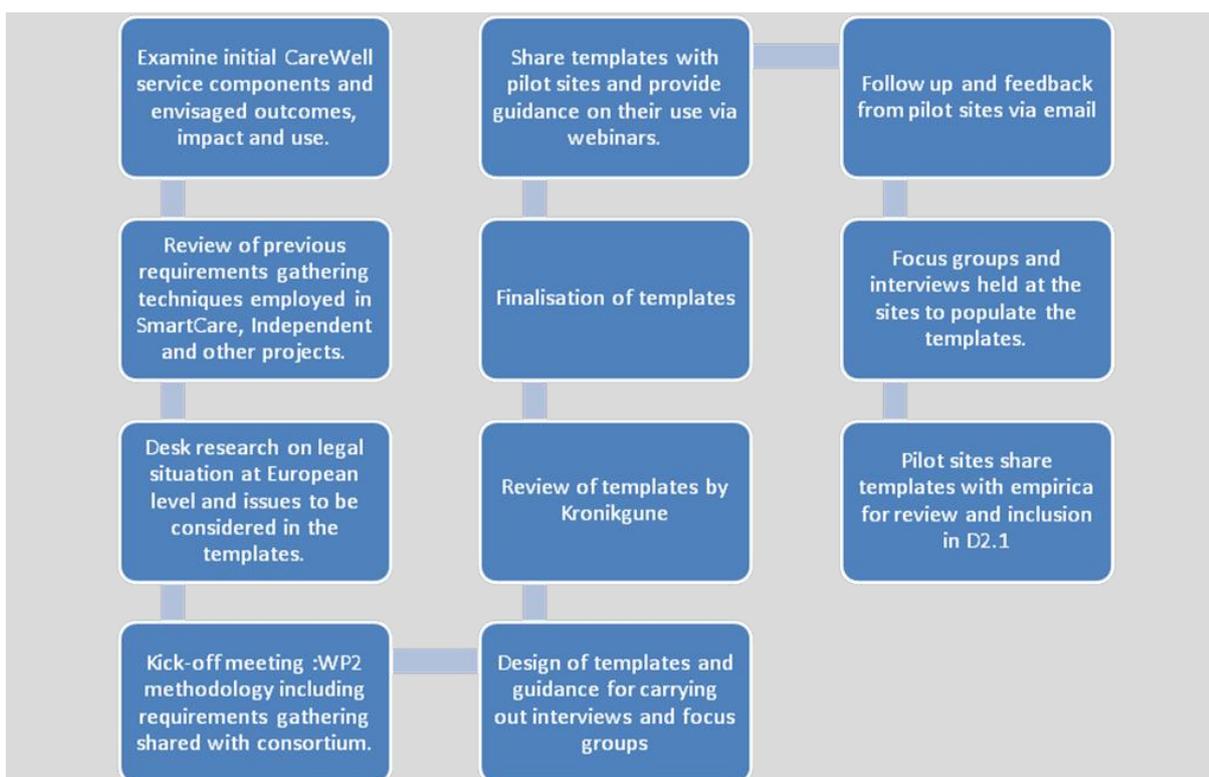


Figure 2: Process adopted for requirement gathering

## 3 CAREWELL PATHWAYS

### 3.1 SERVICE COMPONENTS

All sites will deliver services in line with the two CareWell pathways:

1. Integrated care coordination pathways: Improving communication, coordination and information sharing between health care and social care professionals
2. Patient empowerment & home support pathways: Keep the patients at home maintaining and wherever possible improving their quality of life

In the table below, the services that CareWell will deliver are described in some detail. Not all these service will become available in all participating regions during the lifespan of CareWell.

CareWell integrated care service pathways	ICT functionalities / building blocks	Related ICT solution components
<b>1. Integrated care coordination pathway:</b> Improving communication, coordination and information sharing between health care and social care professionals	<b>Data access &amp; sharing: availability and sharing of patient's clinical data at different levels of care</b>	<b>Electronic Health Record</b> to share all relevant digital information about the patient between healthcare providers in a real-time framework. Also included digital pictures, clinical tests, etc. <b>Electronic prescription</b> to improve drug management, support better prescribing between primary and hospital care, as well as the process of dispensing and administration of drugs .
	<b>Improve the medical diagnostic capability, decrease clinical referrals: virtual consultations</b>	<b>Interconsultations through Electronic Health record</b> between primary care and specialist to make consultations in order to reduce visits to specialists. <b>Virtual Clinical sessions (Lynk Server)</b> between different healthcare providers to share care plans, support team coordination and increase professionals' resoluteness.
	<b>Improved coordination: case management / patient-centeredness</b>	<b>CRM to manage patients in dynamic processes: favours coordination between social and healthcare, resoluteness and patient follow up</b>
<b>2. Patient empowerment &amp; home-support pathway:</b> Keep the patients at home improving their quality of life	<b>Continuous follow up: Telemonitoring</b>	<b>Home-based telemonitoring and telecare</b> to screen patients remotely and intervene early if any evidence of clinical deterioration or social needs appears.
		<b>AAL and Home-based digital platforms</b> offering different services: interactive web-based protocols to promote physical exercise or improve cognitive capacities, reminders to facilitate the adherence to care, daily scheduler... The technological infrastructure for home-based telemonitoring is already in place for some diseases.
		<b>Messaging</b> (email, voice recording) between patients and health professionals.

	<b>Patient access to own data; patient education and self-management</b>	Digital platform ( <b>Personal Health Folder</b> ) where the patient can view reports of their health centre or hospital, consult their drug history or their history of vaccination, check their upcoming appointments... Add the patient information in his Electronic Health Record, using the Personal Health Folder where patient will include his reporting and his doubts or questions to be answered by his doctor.
		Web-based programs where patient can access <b>educational material</b> (documents, videos) to facilitate self-management.
	<b>Improved communication, coordination, advice and response</b>	<b>Call centre: Follow up</b> calls providing health or care advice to maintain a constant track of patients.
		<b>Call centre</b> allowing the coordination between social and healthcarers depending on the citizens' needs (emergencies, health system...)
		<b>Healthcare advisory service</b> via telephone (call centre) or web.

Table 1: Service components of the CareWell ICT integration infrastructure

The table below gives a snapshot of what the participating regions have already in place or commit to deploying within the time frame of CareWell.

Services	Basque Country		Wales		Puglia		Croatia		Lower Silesia		Veneto	
	A	P	A	P	A	P	A	P	A	P	A	P
A=Available; P=Planned for Pilot	A	P	A	P	A	P	A	P	A	P	A	P
<b>Electronic Health Record</b>	A		A	P	A		A		A		A	P
<b>Electronic prescription</b>	A			P		P	A			P	A	
<b>Interconsultations through Electronic Health record</b>	A		A	P	A		A	P		P		P
<b>Home-based telemonitoring and telecare</b>	A		A	P	A			P	A		A	P
<b>Follow up reinforcement calls</b>	A		A	P	A			P		P	A	P
<b>Healthcare advisory service</b>	A		A		A					P		P
<b>Messaging</b> between patients and health professionals.	A			P	A		A	P		P		P
Medical consultation via <b>videoconference</b> .	A		A			P				P		P
<b>Educational material</b> accessible via Web	A		A	P		P	A	P	A			P
<b>Personal Health Folder</b>	A			P		P	A			P		P
<b>Call Centre</b>	A		A		A				A			P



Services	Basque Country		Wales		Puglia		Croatia		Lower Silesia		Veneto	
	A	P	A	P	A	P	A	P	A	P	A	P
A=Available; P=Planned for Pilot												
<b>AAL and Home-based digital platforms</b>	A		A	P		P				P		-
<b>Virtual Clinical sessions</b>		P	A			P		P		P		P
<b>Clinical web portals to share and exchange information</b>		P	A	P		P	A	P		P		P

Table 2: Availability of the service components of the CareWell ICT integration infrastructure

### 3.1.1 Envisaged outcome and impact of the services

The lack of cooperation and communication between healthcare professionals in the treatment of complex multi-morbid patients is a potential source of harm. At the intersection of different care services, information needs to be exchanged in a reliable manner so that treatment of the patient is ideally based on a shared record. The role of incomplete or missing information as well as organisational factors have to be taken into account if one wants to arrive at a complete explanation of the causes of adverse events. In fact, most of the research on the causes of adverse events places a high responsibility on deficiencies in system design, organisation and operation rather than on individuals. Factors to be aware of include an organisation's strategy, its quality management tools and its capacity to learn and adapt.

However, the mere sharing of information is only a first step. Major improvements in the quality of care delivered to patients can only come from evidence based care pathways that coordinate the types of services delivered to multi-morbid patients along the care pathway. In a 2002 survey, two reasons for medical errors were given by American physicians and the public: shortage of nurses (53% of physicians, 65% of public) and overworked, stressed and fatigued healthcare providers (50% vs. 70%). The public also cited too little time with physicians (72%) and not working as a team or insufficient communication (67%).

Challenge	CareWell outcome	Expected Impact
Lack of communication between healthcare professionals leads to errors in documentation and potential harm	Introduction of shared care records	Errors avoided, duplication of efforts avoided
Multi-morbid patients require specific types of services, coordinated over time across different healthcare professionals	Development of care coordination pathways	Delivery of evidence based care
Chronic conditions challenge patients even after discharge from hospital	Development of home support pathways	Improved health literacy of patients and patient autonomy, reduced number of re-admissions to hospital

Table 3: CareWell outcomes and impact in response to challenges

### 3.1.2 Envisaged usage of services

The services deployed in the framework of CareWell are addressed to different categories of users and the usage of the services depends on both the nature of the service and the category of users.

The envisaged use of the services can be summarised in the table below. Although not included in the table other types of healthcare professional users may also be included. Such as physiotherapists, occupational therapists, dieticians, speech and language therapists etc.

Service	Category of users	Usage
1. <b>Electronic Health Record.</b>	Physicians	Creation, update and consultation
	Nurses	
	AHPs (Allied Health Professionals)	
2. <b>Electronic prescription</b>	Physicians	Creation and consultation
	Pharmacists	Consultation and dispensation
	Nurses	Consultation
3. <b>Non face to face consultations through Electronic Health record.</b>	Physicians	Consultation, secure mailing, formulating queries, providing second opinion
	Nurses	
	AHPs	
4. <b>Home-based telemonitoring and telecare</b>	Patients	Passive and active monitoring of health parameters and home environment
	Relatives	Support to patients not autonomous to use telemonitoring and telecare devices
	Community nurses	Support to patients not autonomous to use telemonitoring
	Physicians	Consultation of data from monitoring
5. <b>Reinforcement up</b> calls providing health or care advice to maintain a constant track of patients.	Call Centre operators	Outbound calls to inquiry about patients' conditions/needs
6. <b>Healthcare advisory service</b> via telephone (call centre) or web.	Patients	Inbound calls to the Call Centre or web requests to receive medical advice
	Relatives	Inbound calls to the Call Centre or web requests to receive medical advice on behalf of the patient if the latter is unable to do it by him/herself
	Clinicians	
7. <b>Messaging</b> between patients and health professionals.	Patients	Formulating queries through secure mailing,
	Clinicians	Providing advice
8. <b>Medical consultation via videoconference.</b>	Physicians	Request and provision of advice/second opinion to other physicians
	Nurses	Request of advice to physicians and provision of advice to patients
	Patients	Visual examination by physicians
9. <b>Educational material</b>	Patients	Study
	Relatives	Study on behalf of the patient



10. <b>Personal Health Folder</b>	Patient	Consultation
11. <b>Call centre</b> allowing the coordination between social and health carers depending on the citizens' needs (emergencies, health system...)	Community physicians	Task allocation
	Community nurses	
	Social workers	
12. <b>Virtual Clinical sessions</b> between different healthcare providers to share care plans, support team coordination and increase professionals' resoluteness.	Multidisciplinary team	Virtual meetings for continuous professional development and knowledge sharing
13. <b>Clinical web portals</b>	Physicians and nurses	Sharing and exchange of information on specific patients

Table 4: Envisaged use of the CareWell services

## 4 HEALTHCARE PROFESSIONAL REQUIREMENTS

Key healthcare professional requirements were gathered through interviews and / or focus groups with healthcare professionals who will use the different service components in the CareWell pathways. As healthcare professionals will be users of the service components included in both the integrated care coordination pathway (ICCP) and the patient empowerment and home-support pathway (PEHP) the requirements gathering exercises included questions for both pathways. However, separate sets of questions were provided for each pathways to ensure time allotted to consider each pathway's characteristics, advantages and challenges and what for users to develop appropriate requirements. The exception to this is the Croatian pilot site where their own site-specific questions and requirements were developed.

### 4.1.1 Basque Country pilot site

#### Interview 1:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	March 2014
Venue at which the interview / focus group took place	Clínica Asunción
Duration of the interview / focus group	2 hours
No. of participants in interview / focus group	4
Type of user groups/stake holders involved	Internal medicine, intensivist, cardiologists and medical direction
Recruitment criteria/rationale applied	Experience in patient monitoring

#### Interview 2:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	26/03/2014
Venue at which the interview / focus group took place	Guipuzcoa
Duration of the interview / focus group	
No. of participants in interview / focus group	1
Type of user groups/stake holders involved	Physician
Recruitment criteria/rationale applied	

#### Interview 3:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	30 march 2014
Venue at which the interview / focus group took place	Guipuzcoa
Duration of the interview / focus group	
No. of participants in interview / focus group	1
Type of user groups/stake holders involved	Physician
Recruitment criteria/rationale applied	

**Focus group1:**

Type of event: interview or focus group	Focus group
Date at which the interview / focus group took place	27 march
Venue at which the interview / focus group took place	Primary care center (GROS)
Duration of the interview / focus group	2 hours
No. of participants in interview / focus group	4
Type of user groups/stake holders involved	Physicians, nurses and administratives
Recruitment criteria/rationale applied	

**Focus group 2:**

Type of event: interview or focus group	Focus group
Date at which the interview / focus group took place	26 March 2014
Venue at which the interview / focus group took place	Primary care center
Duration of the interview / focus group	2 hours
No. of participants in interview / focus group	8
Type of user groups/stake holders involved	Physicians and nurses
Recruitment criteria/rationale applied	Care of Pluripathology patients

**Interview 4 (focus group and interviews):**

Type of event: interview or focus group	Focus group/ interviews
Date at which the interview / focus group took place	31st March
Venue at which the interview / focus group took place	Primary care center (Cs JS Bruauga ( Bilbao))
Duration of the interview / focus group	2h
No. of participants in interview / focus group	13
Type of user groups/stake holders involved	3managers, 2 EEH, 1 EGCA,2 TS, 4 family doctor, 1 primary care nurse, 2 internist practicioners
Recruitment criteria/rationale applied	Members of the carewell working group

**Focus group:**

Type of event: interview or focus group	Focus group
Date at which the interview / focus group took place	2 april
Venue at which the interview / focus group took place	HUC
Duration of the interview / focus group	2 hours
No. of participants in interview / focus group	4
Type of user groups/stake holders involved	3 internist practitioners, and a nurse
Recruitment criteria/rationale applied	Working in the Project

## Questions to start the focus groups / interviews with healthcare professional

**What do you think of the services which are currently provided to patients (with or without help of ICT)?**

### **Interview 1:**

Currently services are good, with a clear orientation to chronic patients in recent years, focusing near them (in a primary care). Working in the self-management and self-knowledge.

**Professionals have a** high quality and they also prepared for the new approach.

A lot of remains have to be done, but the approach is successful.

### **Interview 2:**

Services depend to a large extent of the degree of commitment and personal involvement of each professional.

### **Interview 3:**

Referrals to primary care (AP) the most characteristic is their variability both centers as among professionals within a center, both in technical aspects and in the attendance to the patient. But overall I think that the care given is the most adequate.

### **Focus group 1:**

The current services provide coverage for most of the needs of the population. More promotion and prevention. Incorporation of ICTs tools.

### **Focus group 2:**

They are firmly oriented towards health care integration and a continuing care intervention.

### **Interview 4:**

Basically all this allow to access to patient information in the moment that you need the data, you can access to the estimations of the specialist, to the diagnostic tests and all these information is visible at all levels of care.

### **Focus group 3:**

Good health service compared with other health system, although it could improve

**Do you see any advantages or disadvantages in the way services are currently provided?**

### **Interview 1:**

The integration and the continuity of care can generate an improvement that does not exist now. For example the distance between primary and specialized care or the lack of communication among nurses

### **Interview 2:**

Many disadvantages: the agendas are rigid with a lot of bureaucratic acts generated by the system itself. Little capacity of management of their agendas by the health professionals, under-utilization of nurses, performing repetitive tasks without content, absence of evidence of many interventions, unjustified demands of patients, repetitive consultations and waiting lists in complementary tests and specialized assistance with obsolete and little resoluteness consultation models

### **Interview 3:**

We can talk a lot about this, but I'll only mention some aspects which seem to me important.

We have a well-regarded system user where the care is longitudinal and it is one of the fundamental characteristics, although we are yielding some functions related to primary care to other groups as pregnancy, pediatrics, palliative...

We must know to take advantage of the advantage that the proximity to the patient give us our model system.

Many professionals, especially in nursing, do not see the home care more to complicated patients as a priority of its work. Currently the major priority of some professionals is the registration of hundreds of data that are used to evaluate to us, we dedicate too much time to this task a disproportionate time.

**Focus group 1:**

Disadvantage: The patient is captive (quota, Hospital...). There is no possibility to know objectively the qualities and skills of the professionals for a reasoned choice.

Advantage: The doctor and the nurse know the patient and his environment. Accessibility.

**Focus group 2:**

The progressive orientation to the healthcare integration , benefits to the citizen, patient, professional and health service. So, to society in general.

Answer (between 2):

all advantages. Disadvantages: nowadays, it still depends on the attitude of the people.

**Focus group 3:**

Many advantages: public system, Universal, quality, paid for by taxes.

Disadvantages: Poor coordination between the different levels of health, health and social departments. Insufficient involvement of the professionals in those changes which are not directly involved in its activity, etc.

**Do you feel the need to improve / change the way services are currently provided (with or without the help of ICT)?**

**Interview 1:**

Changes are absolutely necessary, but not only now. In medicine the advances in its knowledge make the same progress. The epidemiological expertise, sociological analysis, more adaptation to new technologies will generate changes. The ICT tools will certainly produce their own changes, the concept of application of the medicine in the same way to what is happening in other areas of human activity.

**Interview 2:**

Yes but I think that ICTs are unimportant. Others are the important things. Here we could speak long and hard. As example I invite to read this series of interviews about the necessary changes in the primary care of a number of professionals in this specialty  
<http://saluddinero.blogspot.com.es/>

**Interview 3:**

Primary care nurses will be coordinated with the referral hospital and physician of primary care must be a key element in the care of our more frailty patients without the need of other figures that have recently emerged in our midst. It can happen by a new definition of the roles of nursing and a system of training focused on the fragile patient care.

I am very skeptical with respect to ICTs. In any case should always be a key element with in the model of care.

**Focus group 1:**

Yes. There is always potential for improvement. Communication, information (patients and professionals).

**Focus group 2:**

Of course it is necessary to continue introducing improvement measures. Design assistance routes and establish improvements made. Collaborate with the community and social scope of systematically. It is essential to agree on the form of use of computerized clinical tool, as well as communication between professionals and professional-patient flows.

Answer (between 2):

It is important to continue working in finish with the bureaucracy of the tasks at all and they must be removed from the paper.

**Focus group 3:**

Obviously those areas that overcome the above disadvantages should be improved and others, both from an organisational, training point of view, ICT, etc.

**Do you know what patients think / feel about the services they are receiving? If yes, what is their opinion?**

**Interview 1:**

Since the clinical assumption and from the primary attention of the Tolosaldea region we have had a three-month phase that we have called pilot with 20 monitored patients by 5 professionals. This phase consisted basically in evaluating usability and satisfaction of monitored patients and physicians participating in the use of the application.

We have evaluated through a specific questionnaire to 6 of these people monitored with an average age of 67 years old trying to assess usability and level of satisfaction with some very good results

**Interview 2:**

Much ignorance. Only the official assessment of the region. If I sense that patients are generally satisfied with the attention that is subtracted at primary care level and for example in urgent care. Variability in the opinion on the specialized attention. Complaint by waiting lists

**Interview 3:**

I know some data showing a positive opinion.

**Focus group 1:**

We know some the results of patient satisfaction surveys which are excellent. The survey is very static and would need to redefine it.

**Focus group 2:**

The surveys provide positive ratings. In general, the perception is that the opinion is favorable to the introduction of instruments that are already in the society.

**Answer (between 2):**

Patients receive well this organization. They are coming to us (general practitioners) for information on reports or tests, although sometimes It could be contentious (unknown test to us or with compromised results tests...). The e-prescribing is another great progress which is very appreciated by the patients (and for us, of course)

**Focus group 3:**

We know the opinion of the citizenship, which has a high consideration of Osakidetza healthcare professionals. However, each day is more demanding on the need of the patients to be heard, more dedication of time in consultation, etc.

### Do you currently make use of ICT e.g. telecare or telehealth equipment / services?

**Interview 1:**

Our clinic has an element named **hygehos home** that has the elements marked in this project.

**Interview 2:**

No. Only in some cases I received values from the primary care doctor by email and I do follow up by email (I know it is not legal but gives me same)

**Interview 3:**

For many years (almost always) I have used the phone as a tool for monitoring of my more complex patients, if it is true that not in a systematic way.

I currently have a pluripathology patient who is monitored by means of a software developed by the Asuncion clinic and daily receipt data, weight, heart rate and oxygen saturation.

**Focus group 1:**

Yes; Consultation telephone; Health folder with access for citizens; non-face to face consultations; self-control; dependency reports; video conferencing.

**Focus group 2:**

Widely.

**Answer (between 2):**

Yes, the impression is very good. In the case of the TM is good both for the patient and the professional and in the case of the rest of the TICs, it is unthinkable not to use ICT.

**Focus group 3:**

Yes, in the regular activity

### In comparison to services provided without the application of ICT do you see any advantages or disadvantages?

#### Interview 1:

We believe that services using ICTs have the advantage that already has them. These services function as always, keeping the "classic" services and also implement the benefits of ICTs. If they are doing duplication they are not doing so well.

#### Interview 2:

Unanswered

#### Interview 3:

The family lives in a positive way and feels "more controlled". For my part it is difficult to value. The patients have resorted to the phone always they have been unbalanced and I I've been forced to make a home visit.

#### Focus group 1:

There are obvious advantages: accessibility, saving time for patients and professionals, autonomy. However, the evaluation of all implanted systems is needed.

#### Focus group 2:

Some questions can be answered in a similar way:

Advantages of the introduction of ICTs in the health services offer:

- Continuity of care
- Complete vision of the care process
- Accessibility to the data of the patient against the previous situation where the patient is the carrier of the information
- Concern for the safety of the patient: readability of healthcare documentation and therapeutics.
- Confidentiality in clinical documentation
- Efficiency in the management of health contacts
- Patient access to clinical data

Disadvantages of the introduction of ICTs:

- Dependence on the information and communication systems in daily practice
- Essential systematization of information, even rigidity of management
- Influence organizational workflows of clinical care.

#### Focus group 3:

Clear advantage in terms of coordination of the care paths, knowledge of the patient clinical history, interpersonal communication but risk of depersonalizing when it comes to the clinical interview

### Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?

#### Interview 1:

The coordination path will contribute without any doubt to the advantage of having clinical information that we may need to make decisions at the time that we need that and in the manner that we need to take.

In the empowerment and tM path the physical presence is virtualized and it occurs when it has to happen, not being time-space obstacles to its realization.

The doctor and the nurse can check the patient which makes that the use of other health care resources (consultations, emergencies and hospitalization) is reduced by this existing evidence in this regard. Furthermore your doctor will indicate when to carry out the on-site visit, which makes this gain in value since it will not be as now happens sometimes a mere tracking of constants if not that will occur when the presence is necessary because required a scan or test that so request it. Consultation of presence, which now can count on a percentage of "banal" consultations makes the doctor acting presence, when it should act (monetize the value of care time).

In addition given the frequency of contact or communication with the reading of constants, ratings



etc... it makes both the doctor and the patient feel closer and controlled (self-knowledge and self-control), and having also references of the margins between those who have to keep monitored constants, is generated in the patient a challenge of "having to be within those margins" .

### **Interview 2:**

Several of the interventions proposed by this project has not shown beneficial and may even be harmful (Health folder)

### **Interview 3:**

I think that it could transform the model of pluripathology and fragile patient care. The two pillars on which it is based: the coordination between levels and the patient empowerment are key elements, the primary care nurses have to become in the key element of the process. I think that a model of this type could be well accepted by practitioners of primary care.

### **Focus group 1:**

Unanswered

### **Focus group 2:**

Advantages of the introduction of ICTs in the health services offer:

- Continuity of care
- Complete vision of the care process
- Accessibility to the data of the patient against the previous situation where the patient is the carrier of the information
- Concern for the safety of the patient: readability of healthcare documentation and Therapeutics.
- Confidentiality in clinical documentation
- Efficiency in the management of health contacts
- Patient access to clinical data

Disadvantages of the introduction of ICTs:

- Dependence on the information and communication systems in daily practice
- Essential systematization of information, even rigidity of management

Influence on organizational workflows of clinical care.

Answer (between 2):

- Advantages: on all the immediate access to information and the agility and speed which allows the action on the patient
- Disadvantages: Is the confidentiality of the information well resolved?

### **Target group 3:**

Advantages, in theory and in general, are higher than the disadvantages, provided that it is able to really define the need for them (to whom it is directed, knowledge of tools, etc.) and learn to adapt them to the patients and their needs.

## **Could you think of any factors hampering or facilitating the implementation of CareWell services?**

### **Interview 1:**

Since we just assume that technological factors are that are going to be resolved, we believe that obstacles can come from adaptations to changes by the health organizations, professionals and patients.

Therefore the management of change, demonstration of care improvements with the introduction of these technologies in our professionals has to be done after the observation and the demonstration of the advantages and not only economic improvements but on health posed by these changes.

As for the patients, we have to work in the proximity and the easy access to these technologies and aspects of closeness and sense of control of the disease and self-management, earning the patient and caregivers.

### **Interview 2:**

There is a profound ignorance about the attitude, barriers and facilitators to the use of ICTs by patients and professionals. There are excessive and unjustified expectations about the benefit of ICT both in care coordination between professionals and patients. This is pending of being investigated in our region. On the other hand the modification of the current intelligence services is not in our hand. If this is one of the main tools that the Carewell project has to be clear.

### Interview 3:

This can mean a major change so there will be resistance. Leadership is needed to inspire practitioners with project and commitment to address it because we will have to stop making worthless tasks to others.

A training plan is needed for professionals.

### Focus group 1:

Unanswered

### Focus group 2:

Difficulties:

- Skills and attitudes of professionals
- Resistance to change of professionals
- Investment in technological resources

Enabling factors:

- Systematized and maintained professional training
- Explain the advantages of the instruments that are inserted properly

Answer (between 2):

- Barriers: Attitudes of practitioners, and also patients who want to remain in contact with the different specialists... "...How many more I look better..." It is also necessary that the system works well (computer programs, mostly) because if there are many interruptions at work.
- Facilities: maybe the answer to these problems were faster and that computer systems were solid and solvent

### Focus group 3:

The professional resistance to radical change in some of the cases; important and permanent investment in the necessary technology, adequate selection of target patients...

## 4.1.2 Puglia pilot site

Type of event: interview or focus group	Focus Group
Date at which the interview / focus group took place	28/04/2013
Venue at which the interview / focus group took place	Health-Social District Canosa di Puglia
Duration of the interview / focus group	2 hours
No. of participants in interview / focus group	n. 9
Type of user groups/stake holders involved	Nurses, Specialists, GPs, social workers
Recruitment criteria/rationale applied	Professionals involved in the ICCM

## Questions to start the focus groups / interviews with healthcare professional

**What do you think of the services which are currently provided to patients (with or without help of ICT)?**

Services currently guaranteed satisfy the expressed needs

**Do you see any advantages or disadvantages in the way services are currently provided?**



The advantage is that this service guarantees health and social care tailored on patient needs and the patient empowerment who becomes part of the Care Team.

The disadvantage is lack of communication and integration among professionals and patients. Furthermore there are different ICT tools that not always interact

**Do you feel the need to improve / change the way services are currently provided (with or without the help of ICT)?**

Improve communication aspects, training process among professionals and between professionals and patients

**Do you know what patients think / feel about the services they are receiving? If yes, what is their opinion?**

Patients are happy about the chronic care methodology, happy to take part to the decision making process about his/her own condition, but mainly they feel well looked after and uphold

**Do you currently make use of ICT e.g. telecare or telehealth equipment / services?**

Yes

**In comparison to services provided without the application of ICT do you see any advantages or disadvantages?**

the advantage are:

- Avoid to reach the outpatient clinic or GPs/specialists clinic;
- Avoid to book tests and medical checks/follow up
- Reduction of waiting lists;

Disadvantages

- ICT not homogeneous all over the regional territory;
- Poor competence/training education from professionals in using ICT tools;

**Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?**

Advantages

- Appropriate diagnostic tests avoiding detrimental and useless repetitions
- Facilitate communication and integration among professionals and patients ;
- Centralized data base (virtual base where all the patients data are collected) EHR, where all professionals can have access and where also the patient can have access read and update his data;
- Integration between outpatient clinics and home care;
- Remote monitoring of all patients' parameters and quick health response in case of emergency needs.

Disadvantages

- Upgrade/adapt existing infrastructures

**Could you think of any factors hampering or facilitating the implementation of CareWell services?**

Bottlenecks

- Patients cultural approach;
- Training/education of professionals involved

### 4.1.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 4.1.4 Veneto pilot site

Type of event: interview or focus group	Focus Group
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Date at which the interview / focus group took place	03/04/2014
Venue at which the interview / focus group took place	Local Health Authority nr.2 of Feltre
Duration of the interview / focus group	3 hours
No. of participants in interview / focus group	7
Type of user groups/stake holders involved	Healthcare professionals (doctors, nurses, social workers and other professionals)
Recruitment criteria/rationale applied	Key actors involved in the primary care services

## Questions to start the focus groups / interviews with healthcare professional

### What do you think of the services which are currently provided to patients (with or without help of ICT)?

Services that are provided to patients are quite integrated in Veneto Region in comparison to other Italian regions. The health care and the social care areas has been integrated for a long time, in fact the organizations established by the Veneto Region are called Local Health and Social Authorities and they are responsible for both primary and secondary care through Social and Health districts and hospitals.

### Do you see any advantages or disadvantages in the way services are currently provided?

The advantages are the good integration and the cooperation in the process of home care and hospital discharge process in case of frailty condition. These features lead to a good results in the case of single service.

The disadvantages are related to the co-presence of different priorities in the processes of care. This process of care is by itself slower than a hospital care process but it is also hampered by an information system that actually doesn't allow to see all the data about the patients in one single view. In fact each single service (nursing service, ward service, social workers service) can see only the informations about their own service.

### Do you feel the need to improve / change the way services are currently provided (with or without the help of ICT)?

According to the health professionals an improvement is very needed in the coordination of professional. They have to be more involved towards a common goal and to go beyond their specific tasks and needs. The ICT system should allow to share the information across the different services involved in the process of care, an higher usability of the data by the health professionals and a frequent and easy accessibility to the patient's data. To do this the professionals should be able to access to the system everywhere and at any point of time.

All the professionals should be able to know where a patient is and which are its health conditions. This will allow to recognize the patient's needs and therefore to plan or to reschedule the services according to the most updated situation. This will also lead to an optimization of the working process.

### Do you know what patients think / feel about the services they are receiving? If yes, what is their opinion?

Patients who are already involved in the home care are satisfied of the services delivered. This has been proven by doing a customer satisfaction survey from time to time.

### Do you currently make use of ICT e.g. telecare or telehealth equipment / services?

Every professional who work in the home care service has a PDA in which it is possible to enter all



the services performed and the measurement of the vital signs related to the conditions for which the patient is treated. These services are coded by the ICT system and at the end of the day are uploaded in the system. Moreover, the professionals record all the information related to the measurements (e.g. Blood Pressure, glycaemia, etc...) on a paper folder that stays at the patient's home.

In comparison to services provided without the application of ICT do you see any advantages or disadvantages?

See the previous answers.

#### **Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?**

The Carewell services are seen as potentially good for expanding an approach of proactive medicine among the health professionals; for promoting the empowerment of citizens affected by chronic conditions that have to increase the awareness irrespective to their health conditions; for improving the continuity and the coordination of the care.

#### **Could you think of any factors hampering or facilitating the implementation of CareWell services?**

As every action of change it is possible to foresee a potential resistance to innovate pathways that have been implemented since many years.

Another possible hampering factor is due to the difficulties related to the geographical condition of the territory, quite exclusively mountainous, that has been and it still is a barrier for the access to the networks.

Also the population target presents a possible hampering factor, indeed it is a target of people characterized by no confidence with the technology for the most part.

### 4.1.5 Lower Silesia pilot site

Type of event: interview or focus group	meeting
Date at which the interview / focus group took place	4.04.2014
Venue at which the interview / focus group took place	Falkiewicz Hospital
Duration of the interview / focus group	2 hrs
No. of participants in interview / focus group	7
Type of user groups/stake holders involved	Administration and Clinical users
Recruitment criteria/rationale applied	

### **Questions to start the focus groups / interviews with healthcare professional**

#### **What do you think of the services which are currently provided to patients (with or without help of ICT)?**

They are not satisfactory, patients are not informed as well as they should be. They don't understand the link between different types of ailments they have (e.g. that fungi infection may have its roots in wrong dietary habits, and result in general weakening of immune system and susceptibility to bacterial or viral infections)

#### **Do you see any advantages or disadvantages in the way services are currently provided?**

The disadvantages include: difficult access to information, treating patients as objects of medical treatment without proper guidance through the sickness, lack of in-depth explanation why specific therapies are applied, long lines to the doctors coming from lack of information (patients come to ask basic questions instead of in case of emergency or physical need) which are the cause of the fact that doctors can't spend enough time with all the patients and save it on not explaining what is going on to the patient; lack of proper and general information results in returning infections because patients don't prevent them properly but only cure the symptoms.



**Do you feel the need to improve / change the way services are currently provided (with or without the help of ICT)?**

There is a need for improvement. Better information system based on online platform for communication system could help to improve the situation. Longer time designated for the patients visit in doctor's cabinet will help to solve a lot of problems with returning patients.

**Do you know what patients think / feel about the services they are receiving? If yes, what is their opinion?**

Patients feel disoriented and unsecure because they don't know why are they treated this or that way. Still, they feel happy if they know they have a chance for successful treatment.

**Do you currently make use of ICT e.g. telecare or telehealth equipment / services?**

No

**In comparison to services provided without the application of ICT do you see any advantages or disadvantages?**

The ICT system seems to have many advantages over the current system.

**Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?**

Advantages include: easy access to the treatment data or results of tests whenever patients want, simple way to communicate with healthcare providers, patients don't have to come to the hospital to pick their results or consult easy things, more general and integrated view on health (explaining necessity to eat healthy, be active physically and mentally, maintain beneficial emotional state)

Disadvantages: it will be difficult for the elderly to switch to online system

**Could you think of any factors hampering or facilitating the implementation of CareWell services?**

To facilitate the implementation patients should be well informed about the ITC and be sure that the access to their data is confidential; the problem with some of the patients can be that they are not able to use complicated on-line systems or don't have computers- this could be solved by informing them that a health provider can introduce them to the system and that they can use it for example in one of hospital's rooms



## 4.2 INTEGRATED CARE COORDINATION PATHWAY (ICCP) REQUIREMENTS

### 4.2.1 Basque Country pilot site

#### Healthcare Professional requirements for CareWell Integrated Care Coordination Pathway (ICCP)

##### How will existing workflows be adapted for CareWell Integrated Care Coordination Pathway (ICCP)?

Existing workflows will be facilitated by the fact that some of the issues will be arranged and solved online. Patients could register online, always check their primary personal doctor's schedule, obtain results online and in case of not urgent questions ask them online. Care providers should be obliged to answer patients' questions in designated time and if necessary schedule a visit. Health care providers specializing in different fields will need to communicate to integrate data of specific patient to supply him with general and integrative treatment method.

##### What changes will healthcare professionals have to make to how they work together?

Establish the way they are due to communicate between themselves and with the patients, e.g. if a doctor asks his patient to tests himself for specific disease the laboratory results should come online both to the patient and to his primary doctor who will be responsible for commenting the result, answering patient's questions if they ask any, and scheduling a visit if necessary. E.g. doctors responsible for heart problems will be obliged to keep the primary personal doctor up to date with the patient's results and so on.

##### How will responsibility be split between healthcare professionals?

Every doctor will be responsible for analysing, commenting their patient's results and communicating with the patient.

In the beginning two people will be designated to make 1 hour group introduction for patients to show them how the online system works. Later every doctor will need to give short introduction to his patient if they ask him for that. Once a month all the care providers will gather to discuss how to improve the platform.

##### What are the advantages of CareWell Integrated Care Coordination Pathway ?

Patient must be treated as integral person who during sickness needs to be taken care of physically (In many aspects, which demands application of proper treatments for heart problems, bone problems, infectious diseases etc.), psychologically (which demands trusting relationship between the patient and primary personal healthcare provider), and lifestyle-wise (which demands the primary doctor to have view on all the circumstances of patient's disease: their activity, dietary habits, frequency of occurring infections etc. The doctor should be able to support patient with professional advice in this field and pay attention to the course of patients health. All those may be benefits of implementation of CareWell ICCP.

##### What difficulties do healthcare professionals imagine CareWell Integrated Care Coordination Pathway will bring?

In the beginning the system may be difficult to use for the doctors, it will be time-consuming and cost effort to establish proper cooperation between different sectors of healthcare to gain general view on patient's health. Primary doctors may find it difficult to spend more time with one patient and to communicate with them regularly through online systems. All those problems may be overcome by wise and step by step implementation of the system and work on its improvement.

##### What functionalities do healthcare professionals need / want for Integrated Care Coordination Pathway service processes?

Computers, scanners, printers, a room with computers for patients to don't have one at home, platform of information exchange between different specialists which is absolutely confidential and well protected; manuals available for patients about how to use the system and leaflets to advertise it, general on-line guide for health for the elderly

##### What needs / expectations do healthcare professionals have for ICCP service content?

- online place where patient's results will be stored and can be seen by professional and patient
- email box integrated to the platform allowing exchange of information ONLY between the healthcare professionals and the patient
- online brochure/guide for patients of different age about maintaining general health
- online brochure/guide for patients suffering from some common diseases supporting them with general knowledge about how should they act and whom to contact in case of need
- online registration system with doctors' schedules available
- pricelist of charged services
- platform to communicate between different healthcare specialists (also may be special email box)

#### **What needs / expectations do healthcare professionals have for Integrated Care Coordination Pathway service usability?**

- user-friendly interface
- absolutely confidential, protected
- the service needs to somehow send notifications to the doctor (sms message or screen pop-up when emails/results are obtained and when they date of obligatory response is approaching)

### 4.2.2 Puglia pilot site

## **Healthcare Professional requirements for CareWell Integrated Care Coordination Pathway (ICCP)**

#### **How will existing workflows be adapted for CareWell Integrated Care Coordination Pathway (ICCP)?**

Yes

#### **What changes will healthcare professionals have to make to how they work together?**

- **Professionals Capability to use ICT tools**
- **Capability to team work better sharing information**

#### **How will responsibility be split between healthcare professionals?**

Responsibility of professionals refers to the specific qualification, job description and activities

#### **What are the advantages of CareWell Integrated Care Coordination Pathway ?**

- Avoid repetition of diagnostic and clinical tests
- Sharing clinical and social information which are made available to the patient and the whole care team (of which he is part of)

#### **What difficulties do healthcare professionals imagine CareWell Integrated Care Coordination Pathway will bring?**

- Excessive inflexibility of the regional information system and of the privacy rules and laws that make really difficult and rigid the deployment of the care process
- ICT infrastructure available are not sufficient for the real regional need

#### **What functionalities do healthcare professionals need / want for Integrated Care Coordination Pathway service processes?**

- ICT tools , lap top, Tablet in all the healthcare access points
- Common ICT interfaces among the ones already in use to make easier sharing/using informations

#### **What needs / expectations do healthcare professionals have for ICCP service content?**

Guarantee adequate health/social pathways and care continuity

#### **What needs / expectations do healthcare professionals have for Integrated Care**

### Coordination Pathway service usability?

Do something about cultural models both of professionals and patients

### What other needs / requirements do healthcare professionals have?

More patients Empowerment and better management of them.

## 4.2.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

## 4.2.4 Veneto pilot site

# Healthcare Professional requirements for CareWell Integrated Care Coordination Pathway (ICCP)

### How will existing workflows be adapted for CareWell Integrated Care Coordination Pathway (ICCP)?

The workflow will be modified because new instrument will be introduced. The Patient dashboard will allow to process the needs and requests of the patients in a more integrated way. The workflows have also to be adapted for the telemedicine services such as tele-consultations.

### What changes will healthcare professionals have to make to how they work together?

The healthcare professionals will more connected each other. It will be required also a specific training in the use of the devices and the standard procedures that will be adapted for the CareWell services.

### How will responsibility be split between healthcare professionals?

The responsibility of the clinical case will remain on the GP. The single professionals will be responsible for the services they deliver in a proactive way in order to facilitate the work of each other. Each one will be also responsible for the part of the information flow that is related to their part of services.

### What are the advantages of CareWell Integrated Care Coordination Pathway ?

The possibility to better share information is seen as one of the main advantages. Moreover the sharing of the informations will also influence the communication between primary care services and the hospital care professionals.

The telemedicine module allows patients that have difficulties in movement to stay at home and receive services that otherwise they could get only at the hospital (consultations, exams...). This should carry a minor request for hospitalization and an optimization of the working time.

### What difficulties do healthcare professionals imagine CareWell Integrated Care Coordination Pathway will bring?

The main difficulties seen by the healthcare professionals are:

Possible problems with the connections to the network;

Professionals not so familiar with the technology

Resistance to change process and procedure established since long time.

### What functionalities do healthcare professionals need / want for Integrated Care Coordination Pathway service processes?

Professionals need to be updated on patients information. They want to be able to have a complete view of the patient's status and the services delivered. The primary care also would be able to see the results of hospital examinations already done in order to not duplicate the requests and have updated clinical data. Moreover they want to be trained in the use of these new platform and tools also in relation to the organization of services.

### What needs / expectations do healthcare professionals have for ICCP service content?

They expect to be able to have continuous access to the patients informations which are constantly updated.

### **What needs / expectations do healthcare professionals have for Integrated Care Coordination Pathway service usability?**

There are three main expectations about the new service: it has to be fast and simple to use. It has to be available at any point of time.

### **What other needs / requirements do healthcare professionals have?**

The professional would like to obtain not only the clinical data about the patients but also data about the management of the services and clinical governance.

## 4.2.5 Lower Silesia pilot site

### **Healthcare Professional requirements for CareWell Integrated Care Coordination Pathway (ICCP)**

#### **How will existing workflows be adapted for CareWell Integrated Care Coordination Pathway (ICCP)?**

Existing workflows will be facilitated by the fact that some of the issues will be arranged and solved online. Patients could register online, always check their primary personal doctor's schedule, obtain results online and in case of not urgent questions ask them online. Care providers should be obliged to answer patients' questions in designated time and if necessary schedule a visit. Health care providers specializing in different fields will need to communicate to integrate data of specific patient to supply him with general and integrative treatment method.

#### **What changes will healthcare professionals have to make to how they work together?**

Establish the way they are due to communicate between themselves and with the patients, e.g. if a doctor asks his patient to tests himself for specific disease the laboratory results should come online both to the patient and to his primary doctor who will be responsible for commenting the result, answering patient's questions if they ask any, and scheduling a visit if necessary. E.g. doctors responsible for heart problems will be obliged to keep the primary personal doctor up to date with the patient's results and so on.

#### **How will responsibility be split between healthcare professionals?**

Every doctor will be responsible for analysing, commenting their patient's results and communicating with the patient.

In the beginning two people will be designated to make 1 hour group introduction for patients to show them how the online system works. Later every doctor will need to give short introduction to his patient if they ask him for that. Once a month all the care providers will gather to discuss how to improve the platform.

#### **What are the advantages of CareWell Integrated Care Coordination Pathway ?**

Patient must be treated as integral person who during sickness needs to be taken care of physically (In many aspects, which demands application of proper treatments for heart problems, bone problems, infectious diseases etc.), psychologically (which demands trusting relationship between the patient and primary personal healthcare provider), and lifestyle-wise (which demands the primary doctor to have view on all the circumstances of patient's disease: their activity, dietary habits, frequency of occurring infections etc. The doctor should be able to support patient with professional advice in this field and pay attention to the course of patients health. All those may be benefits of implementation of CareWell ICCP.

#### **What difficulties do healthcare professionals imagine CareWell Integrated Care Coordination Pathway will bring?**

In the beginning the system may be difficult to use for the doctors, it will be time-consuming and cost effort to establish proper cooperation between different sectors of healthcare to gain general view on patient's health. Primary doctors may find it difficult to spend more time with one patient and to communicate with them regularly through online systems. All those problems may be overcome by wise and step by step implementation of the system and work on its improvement.

#### **What functionalities do healthcare professionals need / want for Integrated Care Coordination Pathway service processes?**

Computers, scanners, printers, a room with computers for patients to don't have one at home, platform of information exchange between different specialists which is absolutely confidential and well protected; manuals available for patients about how to use the system and leaflets to advertise it, general on-line guide for health for the elderly

#### **What needs / expectations do healthcare professionals have for ICCP service content?**

- online place where patient's results will be stored and can be seen by professional and patient
- email box integrated to the platform allowing exchange of information ONLY between the healthcare professionals and the patient
- online brochure/guide for patients of different age about maintaining general health
- online brochure/guide for patients suffering from some common diseases supporting them with general knowledge about how should they act and whom to contact in case of need
- online registration system with doctors' schedules available
- pricelist of charged services
- platform to communicate between different healthcare specialists (also may be special email box)

#### **What needs / expectations do healthcare professionals have for Integrated Care Coordination Pathway service usability?**

- user-friendly interface
- absolutely confidential, protected
- the service needs to somehow send notifications to the doctor (sms message or screen pop-up when emails/results are obtained and when they date of obligatory response is approaching)

## **4.3 PATIENT EMPOWERMENT AND HOME-SUPPORT PATHWAY (PEHP) REQUIREMENTS**

### 4.3.1 Basque Country pilot site

### 4.3.2 Puglia pilot site

## **Healthcare professionals requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP) services**

### **How will existing workflows be adapted for CareWell Patient Empowerment and Home-support services?**

It is possible only after having adequate the existent infrastructure on the territory.

### **What changes will healthcare professionals have to make to how they work together?**

Team work implies sharing of information, systematic use of consultations in order to treat patients not just focusing on the pathology or one specific need but using an olistic approach and multi-dimensional (clinical, social psychological..)

### **How will responsibility be split between healthcare professionals?**

Responsability of each professional depends on the qualification , job description, and activities and procedures carried out

### **What are the advantages of CareWell Patient Empowerment and Home-support services?**

They are all in favour of the patient who doesn't need to move to reach the services

### **What difficulties do healthcare professionals imagine CareWell Patient Empowerment and Home-support services will bring?**

Difficulties underlined are always related to lack of training/education

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service processes?**

Fundamental need: proper training

Expectation : more simple and more dynamic management of service delivered

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service content?**

More information is needed

Therefore more involvement in care pathways

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service usability?**

Expectations : easier management of information therefore shared care pathways

**What other needs / requirements do healthcare professionals have?**

As said already more ICT tools and better distribution on the regional territory

### 4.3.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 4.3.4 Veneto pilot site

## Healthcare professionals requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP) services

**How will existing workflows be adapted for CareWell Patient Empowerment and Home-support services?**

A workflow on PEHP has to be introduced in the current services of the Primary Care. The GP will evaluate the need of an assisted tele-monitoring and he will activate the process through the Primary Care District, assigning a specific care plan.

**What changes will healthcare professionals have to make to how they work together?**

The healthcare professionals will more connected each other. It will be required also a specific training in the use of the devices and the standard procedures that will be adapted for the CareWell services.

**How will responsibility be split between healthcare professionals?**

There will be an increasing responsibility of the nurses that is in charge of the assistance of the patients who will need the assisted telemonitoring and their education. Anyhow the responsibility of the overall health status of the patients remains on the GP and the health professionals take responsibility for the services they deliver.

**What are the advantages of CareWell Patient Empowerment and Home-support services?**

The cares delivered at home will increase. The patient will learn to better recognize the risk signals connected to its pathologies. A major control in the health trend, will allow both the GP and the other professionals to anticipate the correct response to potential health problems.

**What difficulties do healthcare professionals imagine CareWell Patient Empowerment and Home-support services will bring?**

The main difficulty could be related to the fact that the most part of the target population is not confident using technology and so it could be foreseen a longer time for the education of patients in the use of devices or online materials.

Another difficulty could be the connection to the network and the access to the broadband in some

parts of the territory served by the local health authority.

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service processes?**

As in general for the services, if the pathways will work as expected, an improvement of the quality of life of patients will be a primary outcome. As secondary outcome it is expected a decrease of the hospitalization and a more appropriate response to the patients' needs ensuring a better continuity of cares at home.

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service content?**

The cares delivered will be more tailored on the effective needs of every and single patient. More data available will allow to take initiative in action in the field of pro-active medicine instead of the reactive one.

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service usability?**

The patients will feel more involved in the process of care. This will make them more aware of their pathologies, of the risk signals that they can perceive and overall to feel "empowered" in the management of their own health status.

#### 4.3.5 Lower Silesia pilot site

### Healthcare professionals requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP) services

**How will existing workflows be adapted for CareWell Patient Empowerment and Home-support services?**

Patients will have better opportunity to analyse their results at home and a chance to register and keep in touch with their health-provider from home.

**What changes will healthcare professionals have to make to how they work together?**

Communicate through online platform on daily basis, be able to schedule charged home visit with a patient in case of emergency

**How will responsibility be split between healthcare professionals?**

Every doctor will be responsible for analysing, commenting their patient's results and communicating with the patient. In the beginning two people will be designated to make 1 hour group introduction for patients to show them how the online system works. Later every doctor will need to give short introduction to his patient if they ask him for that. Once a month all the care providers will gather to discuss how to improve the platform.

**What are the advantages of CareWell Patient Empowerment and Home-support services?**

A person who takes care of the elderly patient on daily basis as well as the patient himself will be better guided and able to deliver needed help consciously.

**What difficulties do healthcare professionals imagine CareWell Patient Empowerment and Home-support services will bring?**

Assessment of responsibility of informal caretakers in case when the patient himself can't have insight into the online platform (e.g. because of disability)

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service processes?**

If such a person exists, it will be needed to allow an informal caretaker who is in touch with the patient on daily basis (e.g. a nurse, a family member) to have insight into the services and be a medium of communication between the patient and the health professionals. The best would be if this person would be designated by the hospital; however, if it's not a member of the hospital community this person should be lawfully responsible for maintaining contact between the

patient and the system. This person will deliver doctor's messages to the patient if he is not able to read or understand them himself. Caretaker should visit the doctor together with the patient, memorandum of understanding of patients and caretaker's responsibilities towards the service between the patient, informal caretaker and health professional should be prepared.

#### What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service content?

- online place where patient's results will be stored and can be seen by professional and patient
- email box integrated to the platform allowing exchange of information ONLY between the healthcare professionals and the patient/patient's responsible
- online brochure/guide for patients of different age about maintaining general health
- online brochures/guides for patients suffering from some common diseases supporting them with general knowledge about how should they act and whom to contact in case of need that will be send to the patient according to their state of health (e.g. 'Dealing with common cold', 'Dealing with swelling' etc.)

#### What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service usability?

- user-friendly interface
- absolutely confidential, protected

## 4.4 CROATIAN PILOT SITE BOTH ICCP AND PEHP REQUIREMENTS FROM GENERAL PRACTITIONERS

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	March 20 <sup>th</sup> , 2014 April 1 <sup>st</sup> , 2014 April 10 <sup>th</sup> , 2014
Venue at which the interview / focus group took place	Zagreb healthcare centres (Tuškanac 23, Bartola Kašića 6, Kruge 44)
Duration of the interview / focus group	1h
No. of participants in interview / focus group	3
Type of user groups/stake holders involved	General Practitioners
Recruitment criteria/rationale applied	Doctors taking part in CareWell project.

### Interview Questions

#### 1. Which parts of the Zagreb city do you cover and how many patients do you have in your area?

Each GP covers a very specific part of the city which is defined in advance. However, it may happen that one doctor might even have patients from parts of the town that are not in his designated geographical area. On average they cover between 1500 and 1800 patients per GP.

#### 2. Out of the total number of patients how many patients are chronic patients?

This information will vary for different areas of town, on average this is 30-35% but in some cases even more.

#### 3. How often do chronic patients come to your office in comparison with other patients?

It is very different, and it depends from patient to patient. Some chronic patients come to doctor's office every day or few times a week, and some do not show up at all. They just call by phone and ask for the medications that they regularly take – which is not good.

#### 4. What is the average length of a typical visit of a chronic patient?

Usually it takes between 15 minutes and half an hour. In some cases when patient has not visited

the doctor for a while, it might take even longer.

#### **5. What is the usual routine when the patient comes to your office?**

The visit begins with a short discussion to see what was going on since the last visit – just to understand what is going on with patient, is he/she coming just for the regular visit, or is he/she having a specific problem. As well, standard measurements are performed during the visit – blood pressure measurement, sugar blood pressure, SpO2 or other according to the need. Doctors also do tests for the mobility of joints if patient has hard time with moving around.

#### **6. How often do you see patient suffering from COPD and another chronic disease?**

Usually once a month they come to doctor's office or just call to get medications. At least once in three months they should come for the office visit.

#### **7. When patient calls you directly, what is it that they need in most cases?**

Most of chronic patients stop taking medications therapy after their condition has improved a bit. Afterwards, usually they feel bad again and that is the most usual reason for calling in.

#### **8. How do you choose patients that need to get field nurse visits?**

Those are in most cases elderly people who are at home and have one or more chronic diseases. One of the most important criteria is the need for education of such people – for example those that have been diagnosed with diabetes and have hard time with walking. So main criteria is elderly people who cannot walk easily so it is hard for them to come to doctor's office. And of course, they have one or more chronic diseases that need to be managed actively.

#### **9. What kind of information would you like to get as feedback from field nurse, when she is visiting the patient? Do you need that info instantly or do you ask for feedback later?**

Standard medical measurements depending on the disease. Doctors need blood pressure measurement or sugar level measurement in case the patient is feeling bad – that will allow them to understand what is going on and change the therapy instantly if needed. Sometimes they will even take a photo with smartphone and send it to doctor via WhatsApp or email – that helps a lot! Sometimes, if the nurse thinks it is urgent, she will call the doctor and let know of measurement data, straight from the field. However, in most cases it is good enough to have a meeting once or twice a week to go through the data that nurse has collected.

#### **10. Do you have enough time to educate chronic patients about their disease, healthy diet, exercise, medications therapy or other important topics?**

Doctors usually do not spend much time on educating patients. When in doctor's office, patient gets basic education from nurse but most of info and educational content comes from field nurses during the home visit. Sometimes, support groups have been organized where patient can come to get info on their disease. However, the response was not very high so most focus on education is done during home visit. Apart from only educating patients, field nurses educate the whole family as well as any informal caregiver that is taking care of the patient.

#### **11. How do you educate yourself? How do you prepare the education materials for patients?**

Elderly doctors rarely use internet as source of education. They use books, specialist magazines and take obligatory courses to continue with their education as this is mandatory to keep their license.

#### **12. How often patients have some kind of caregiver as a help – family, friend or paid help?**

In most cases there is someone to help. Either friends or family or they pay for professional help. In case the patient has no friends or family and cannot afford to pay for help then we arrange field nurses or home care workers to visit those patients on more regular basis.

#### **13. Can patient or patients' caregiver call field nurses on phone and when can it be done?**

Field nurses can be reached on the phone in the morning, between 7 and 9 o'clock, before they go out for patient's visits. But also, most field nurses give their mobile phone numbers to their patients so they can be reached all they long – patient sometimes just send SMS or give a call if they need something.

#### **14. How do you find out that your patient has been hospitalized?**

Sometimes patient's caregiver informs the doctor and in some case the doctor will find out from medical documentation. On average it is 50-50 distribution.

**15. If you make any medical measurements when the patient is visiting your office, how is that data stored? Is it available to field nurses and vice versa?**

At the moment doctor's record and field nurses' records are not connected. The only way of sharing the data is by giving info during the meetings – no sharing of written or digital data.

**16. Do you have a PC in your office? Do you have any kind of IT support?**

Yes, doctors are using IT system for GP offices. There is general IT support in the health centre and there is support from the health IT system provider. In general doctor experiences lots of issues with the IT system that they are using – every once in a while, it needs to be remotely managed by IT professional and it gives medical staff a lot of trouble in everyday work.

**17. How do you use your PC in everyday work? What for?**

All activities need to be recorded in IT system. Therefore, doctor needs to register patients visit, write what was done during the visit, define therapy, diagnosis and provide info on diagnostic procedures which is needed for insurance company to cover the cost. If there was a hospitalization, the patient will usually bring the discharge letter so the data is transferred in GP's IT system manually. Everything that was done or recommended to the patient needs to be recorded in GP's IT system.

**18. Are you using a smartphone?**

No.

**19. Are you using your PC for communication with other medical staff?**

Sometimes if it is needed, doctors send emails so they use PC for communication with field nurses or secondary care. However, it takes too much time, so in most cases they need to communicate directly.

**20. How do field nurses cooperate with home care teams?**

They work well together, exchange information about patients when it is needed. Each team is performing their activities and in most cases work well together. Communication is organized on regular bases in form of weekly or bi-weekly meetings – but this will vary from one medical team to another.

**21. How many chronic patients per year get referred to physiotherapy in their home?**

Last year about 40 patients were prescribed with the physiotherapy in house, on average and per GP.

**22. Do you have access to medical data that was measured by field nurse during the home visit?**

Only when doctor sits down with nurse to discuss about the patient that she has visited. Unfortunately, that info is not available on PC, for now.

**23. Do you have access to results of specialist examinations that patient has been on?**

Only lab results are available on our PC. Other info needs to be provided by patient. They bring the results when they get them at secondary care institution.

**24. How would you improve the education of chronic patients and their informal caregivers?**

Ideally doctors would like to have all patients on workgroups where they could educate more than one patient at the time – that would be much more efficient. However, people rarely show up on such groups so it is not very effective.

**25. Do you think that chronic patients need psychological and social help?**

That is always useful. Doctors and field nurses always need to understand their patients, their needs, what is going on in their family, what stresses them and what makes them happy.

**26. The idea of this project is that patient could always reach out to field nurse via communication technology. What do you think about that idea? How should it be organized?**

Direct communication via phone or other digital channel is good. However, physical contact is needed and should not be replaced by technology. Technology is good if it helps but meeting the patient in person and talking to them cannot be replaced by technology.

**Requirements specification**

Technology/functionality related requirements	Service process related requirements	Other requirements
Automated process for medical data input (measurements, notes, questionnaires) during the field nurse patient visit.	Define new procedure on how to handle data provided by field nurse during the field patient visit with focus on data review and regular feedback. Two streams need to be covered: regular procedure and urgent procedure.	
Central digital storage place (PHR) for all data inputted by visiting nurse during the patient field visit.		
IT communication tool (message exchange) for internal communication between doctor and field nurse		
Integration of EMH central storage (PHR) with central healthcare record		
Integration of GP's office application with the central healthcare record.		

#### 4.5 CROATIAN PILOT SITE BOTH ICCP AND PEHP REQUIREMENTS FROM NURSES

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	March 14 <sup>th</sup> , 2014 March 19 <sup>th</sup> , 2014
Venue at which the interview / focus group took place	Zagreb healthcare centre (Martićeva 63, Zagreb)
Duration of the interview / focus group	1h
No. of participants in interview / focus group	2
Type of user groups/stake holders involved	Field Nurses
Recruitment criteria/rationale applied	Field nurses which are participating in CareWell project.

##### Interview questions

#### 1. In your everyday work, what is the number of GP's that you cooperate with And how many patients do you cover? Which areas do you cover?

Field nurses need to cover a certain geographical area, or certain parts of the town. However, that does not mean that field nurse only works with doctors from their designated area. Since patient can choose the doctor that they would like to be their GP, sometimes field nurse needs to work with GP that is not situated in their health centre or area. On average, each field nurse will have to cooperate with 2-3 GPs. Regarding the number of patients, each nurse should cover around 5100 citizens.

#### 2. How many chronic patients do you cover?

This will depend on the part of the town. In areas with mostly elderly people it is about 70% of

chronic patients while in other parts of the town it is less. On average, let's say 30%.

### **3. How often do you visit chronic patient in their home?**

Usually the nurse will decide depending on the condition of the patient. The regulation says at least twice per month for patients that are getting in-house care. For some patients it might be much more and then as the condition gets better it might decrease to even once a month. When the patient needs to get educated about the disease, the field nurse might visit him/her even 10 days back to back.

### **4. Do you also educate other members of the patient's household?**

Every member of the household should get educated to be able to help the patient first-hand. Not only that nurses educate all family members, they often give medical advice to them as well.

#### **4.1 Do you use any education materials or is it primarily verbal communication.**

Mostly verbally, but some field nurses do prepare written materials, guides, food menus and similar. However, that cost is not covered by the healthcare system.

### **5. How long does one visit last and which activities do you usually perform?**

On average the visit lasts about 45 minutes to one hour, varying from patient to patient. At the beginning nurse will do the reassessment of the condition. What has changed, did it change to better or worse, is the patient keeping up with the medication treatment, taking medical measurement regularly and so on. Afterwards, the nurse will perform regular medical measurements depending on the disease type and see the trend compared with the measurements that were performed by the patient. Finally, nurse will educate patient on how to minimize the impact of the disease and how to follow the treatment that was prescribed in best possible way – nutrition or regular exercises

### **6. How are working hours of field nurse organized?**

The problem with working hours is that in most cases activities are performed in the morning hours. Therefore, if there is a chronic patient that is still employed, the nurse cannot give them a visit. A good idea would be to organize a third shift, so that field nurses could give support to their patients even during the night. They might contact the field nurse even on the daily basis – some come to the office and some call on the phone.

### **7. Do your patients or caregivers contact you directly? If yes, then how often?**

Yes, they do. Nurses usually give them their mobile phone contacts so they develop some kind of personal relationship - that is very important.

### **8. What is the primary reason that the doctor would prescribe the field nurse service?**

In most cases the reason is that patient is at home and not hospitalized, so they need to be educated or get basic healthcare service and be able to take care of themselves. Sometimes those patients are very old people that can hardly take care of themselves, so they need field nurses to visit and reassess the health status. However, field nurses do much more than that – often they are psychological support to patients or caregivers or they might even indicate that there is the need for the social care to come and do their work.

### **9. Who makes plans for the patient visit? GP or field nurse?**

In most cases the nurse will plan her weekly or monthly schedule. However, GP will also ask her to go and visit a specific patient and let her know what needs to be done.

### **10. What type of medical or non-medical equipment do you carry for field visit?**

Standard healthcare measuring devices: blood pressure monitor, glucometer, urine tests, some equipment that we use for new-born children, weight scale for new-borns. Camera is not provided by healthcare system but nurses sometimes have camera on their phone so they take photos and send to doctor using their phone camera.

### **11. Do take any education yourself? How do you find educational materials?**

There are professional educations organized on monthly basis to be able to keep up with the new trends in medicine. On top of that regional health centres also organize various workshops twice per month – covering various topics. Finally, field nurses that are self-motivated also get educational materials on internet or in medical magazines.

### **12. How and when do you provide measurement results to the GP?**

Each nurse is keeping a record which is separate from the doctors' record, so data is never in the same place. If the measurement results are not normal, then the nurse will let the doctor know. If

all is fine, then there is no need to transfer the results to the doctor. Unfortunately, data collected by field nurses is not stored in digital format and cannot be shared with doctor via PC.

**13. Are you using any kind of IT system? Is your IT system connected with the system that is used by doctor?**

Yes, nurses are using a simple IT system but it is closed only for the field nurse organization. That system cannot be used to share the findings with other medical professionals that take care of the patient.

**14. Then how do you share your findings with the doctor? How often?**

It is done in conversation with doctors, during informal meetings, at least once a week. But this depends from one healthcare team to another. Nurses even call doctors from the field if they think that doctor's opinion is needed at once. It is much easier to communicate with the GP if they are situated in the same health centre as the nurse – i.e. when offices are close by.

**15. Do field nurses perform any kind of physical therapy?**

Only active and passive stretching, to test for the mobility of joints, which is important for elderly patients. All other activities regarding physical therapy are performed by physiotherapist. Field nurses only supervise the process of physical therapy – is it and how much helping the patient and if there is need for additional visits by physical therapist.

**16. Who is controlling the work of field nurses?**

Unfortunately no one. There is no control on work quality, efficiency or how they help their patients. Patient satisfaction is not measured so field nurses are more or less self-managing individuals. The only thing that is being measured is the number of the visits that have been done – system does not care what was done and how well it was done. That is sad!

**17. How does field nurse know that patient has done some kind of specialist exam?**

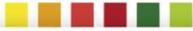
Only if the patients doctor or patient personally tells them. That record is not available to the field nurse. However, when there is good communication between field nurse and doctor that info should be sent across.

**18. The idea of this project is to enable the communication between patient and field nurse. Is there specific time of the day and day in the week when it would be most appropriate to arrange time slots for consultation?**

At the moment nurses are available on the phone in the morning before they leave for field visits. Between 7.30 and 9 o'clock. As well people can come to field nurses office or even call her on mobile if she agrees. What needs to be done is to enable the communication in the afternoon and maybe during night. There are chronic patients that are working and can only contact the nurse in the afternoon when they have finished their daily work routine.

### Requirements specifications

Technology/functionality related requirements	Service process related requirements	Other requirements
New role defined in EMH system – Social Care Worker.	Detailed procedure defining the WoW in cooperation of field nurses and social care – how, when and what type of data is imputed and shared internally.	Provide education/training to field nurses on how to provide psychological support to care givers.
Social care reporting tool built in the EMH Android app and web application (questionnaires or notes).	Define new service process to be followed by all field nurses while performing field work.	Enable specific content that will help field nurses in providing psychological support to care givers.
IT communication tool (message exchange) for internal communication with doctor	Define specific time window for phone communication between field nurses and patients.	



<p>New medical sensors for better chronic disease management, all Bluetooth enabled: ECG and spirometer.</p>	<p><i>PHCP related:</i> Detailed process for planning and delivery of psychological support to care givers.</p>	
<p><i>PHCP related:</i> Educational tool for field work running on android devices (smartphone or tablet) – covering disease info, therapy and side effects, nutrition, exercise...</p>		
<p><i>PHCP related:</i> Tool for providing psychological support to caregivers, which is running on android devices (smartphone or tablet). Content/guidelines to be provided by psychologist.</p>		



## 5 PATIENT AND INFORMAL CARER REQUIREMENTS

Key patient and informal carer requirements were gathered through interviews and / or focus groups. These focus group interviews with patients and informal carers help the project to learn more about the group specific needs regarding the development and implementation of CareWell pathways.

As patients and informal carers will be users of the service components included in the patient empowerment and home-support pathway (PEHP) the requirements gathering exercises focused on this pathway, rather than the integrated care coordination pathway (ICCP) where they are unlikely to be direct users of the service components. This is with the exception of the Basque Country pilot site which assessed the nature of their service components for the ICCP pathway and came to the conclusion that patient and informal carer requirements should also be gathered for this pathway.

### 5.1 PATIENT EMPOWERMENT AND HOME-SUPPORT PATHWAY (PEHP) REQUIREMENTS

#### 5.1.1 Basque Country pilot site

##### Interview 1:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	September/November 2013
Venue at which the interview / focus group took place	Clínica Asunción
Duration of the interview / focus group	Monitoring patients during 3 months
No. of participants in interview / focus group	6 interviews
Type of user groups/stake holders involved	Patients with chronic diseases
Recruitment criteria/rationale applied	Chronic pathology and possibility to Access to the programme (Web in PC o Smartphone)

##### Interview 2:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	
Venue at which the interview / focus group took place	Gros (Guipúzcoa)
Duration of the interview / focus group	
No. of participants in interview / focus group	
Type of user groups/stake holders involved	
Recruitment criteria/rationale applied	

##### Interview 3:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	March 2013



Venue at which the interview / focus group took place	Guipúzcoa
Duration of the interview / focus group	
No. of participants in interview / focus group	1
Type of user groups/stake holders involved	Relative
Recruitment criteria/rationale applied	Chronic patient 's relative

**Interview 4:**

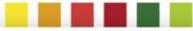
Type of event: interview or focus group	Interviews
Date at which the interview / focus group took place	27 march- 2 April
Venue at which the interview / focus group took place	Comarca Uribe
Duration of the interview / focus group	30 minutes
No. of participants in interview / focus group	8
Type of user groups/stake holders involved	Patients and careers
Recruitment criteria/rationale applied	Plurypathology

**Interview 5:**

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	31 March- 3 april
Venue at which the interview / focus group took place	Hospitalization and external consultation
Duration of the interview / focus group	30minutes/patient ( 270 minutes )
No. of participants in interview / focus group	9
Type of user groups/stake holders involved	3 physicians
Recruitment criteria/rationale applied	Plurypathology and complex chronic patient

**Interview 6:**

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	31 march-3 april
Venue at which the interview / focus group took place	Home and hospital
Duration of the interview / focus group	30 minutes
No. of participants in interview / focus group	4 patients in primary care + 4 patients in hospital 2 careers in primary care + 3 careers in Hospital
Type of user groups/stake holders involved	EGC, EE, Nurse of primary care, doctor of primary care and physician
Recruitment criteria/rationale applied	Pluripathology patient ( 4) and patients using TM ( 2 in primary care)



## Patient and informal carer requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)

### What are the advantages of CareWell PEHP?

#### Interview 1:

Responses about the advantages have oriented to the security provided by a system that feel like they have a professional which tracks them.

#### Interview 2:

-More comfortable, decrease the number of trips to the primary care center

#### Interview 3:

-One of the advantages is that it will be more comfortable for the patient and the family because it won't have to go to the primary care center

#### Interview 4:

-A faster and immediate assistance.

-I do not see benefits for older persons.

-Don't have to go to the hospital or primary care center and give greater independence and safety.

-Easier, safe and comfort. Access to the health data without moving.

-Many. In my opinion as a career and caring for my mother, but living in another municipality, the possibility of accessing online to the health data makes the life easier and I think that professionals control more closely the health of my mother.

-Up-to-date knowledge of the health state. They can take steps to correct what is needed, if they health professionals know how you are and know what you've got on your health.

-Knowledge of the latest state of health and it seems is safer.

#### Interview 5:

-More information and knowledge of the illness.

-More capacity of self-care.

-Direct communication with your doctor via messaging (e-mail).

#### Interview 6:

-Always it is nice to know the symptoms a little better in case you have them and I feel safer with TM

-There is greater control by professionals with the TM and helps to the patient empowerment

-Prefer to attend consultation doctor / nurse if I have questions or want to see something

-I prefer to have personal contact with professionals

-The early detection of any anomaly

- Give peace to have more control

-Are good, especially the telecare since you have an answer immediately and the patient receives calls from the healthcare professionals to know about their health

-It allows to know more about your disease

-The patient does not feel able to use these resources and he has previously refused to be included in a TM program.

- The patient care can be immediate

-The health control is more frequent with TM, there are answers to small changes in its state before the situation becomes worse and it is easier to access to their health information.

### What difficulties do patients and informal carers imagine CareWell PEHP will bring?

**Interview 1:**

The difficulty is in the technologies management

**Interview 2:**

I think that any

**Interview 3:**

The difficulty in the management of the parameters and the data transfer

**Interview 4:**

- The learning of these mechanisms is difficult to many older people.
- Too many difficulties
- If everything is explain correctly he doesn't see difficulties
- The use of new technologies and equipment
- He/She believes that some people, especially the older people or people with fewer studies are not going to easily understand the technical aspects of this route. He also says at the end "the machines are going to eat us" and that if a person can control all those data at the end there will be fewer jobs.
- The ability to use computer or technology.
- To operate with a computer I would need help, (I ask help to my grandchildren).

**Interview 5:**

- I don't trust in the measurement of certain clinical parameters that must be sent by the professionals.
- Lack of knowledge when he has to correctly interpret relevant symptoms.
- Technical difficulties when it comes to use ICTs.

**Interview 6:**

- The devices can malfunction and you get nervous when they do not work.
- Some patients are very old
- The use of the instruments and the computer access must be easy, the possibility of inadequate performance of the instruments.
- The patients are older people and have certain disabilities to handle well in the functionality of the internet, TM....They would need the help of family members who are trained.
- I am not trained to use these resources, and I am not going to try (85 years, lives alone, part-time and low caregiver).
- I don't know how to use a computer
- Learning of the handling of the machine it is difficult, and it cost too much to the patient
- The machine does not work properly
- The patient gets nervous with an rare data or anomaly.
- I am very old to use devices, I get very nervous with new technologies

### What changes would you have to make if CareWell PEHP was part of your life?

**Interview 1:**

The changes which occur are positive. These changes make the patient track of his own illness, with the consequence that has self-awareness of the same. The patient must follow its own constant and know the deviations that are happening with respect to the criteria of normality. The fact of having to communicate through an evolving with the doctor or nurse also makes the patient make their own evolutionary that complemented the history.

**Interview 2:**

-I think that any

**Interview 3:**

I need to learn about computers

**Interview 4:**

- Learn to use machines and to make decisions on our own
- No change if you don't use them
- Change of the routine and technological learning.
- Learn how to use them.
- Don't know, basically change in the mentality
- Do not know the changes that she would have to make, she says that she is retired and she has a lot of time
- Changes: material, information and preparation to use ICT.

**Interview 5:**

- Have knowledge of available information systems, learn the use of them, believe in the possibilities of ICT..., ultimately change the mentality that allows you to believe that this route is better to usual care

**Interview 6:**

- very few. It's like taking your drugs. You know when you have to do and it does not take more than 5 minutes. Learn how to use the equipment and resources that are available. Once done, attach the use of them to their routines
- have the devices and that teach us to use them so that they will become a habit
- The truth is that I prefer to go to the primary care doctor to all the necessary controls. I follow everything what I say
- Do not know
- very few. It's like taking the medicines. You know when it's your turn to do so and does not take more than 5

**What requirements do patients and informal carers have for PEHP service processes?****Interview 1:**

They are basically technical needs, from access to the technology needed to handle conditions that TM requires them. The good news is that in our experience and monitoring patients with ages greater than 70 years, his basic handling of keyboard and screen is already extended, and this access and management of these technologies has certainly not only just begun.

- Also may require the presence of a caregiver TM whatever you operate this tool, which is not always possible, so we would have patients who can and others who cannot access this service.
- We have seen relatives, neighbors, in the case of residences cannot provide response to this need the headcount of the same, and even the pharmacies that are always close to the population.

**Interview 2:**

- As and when measured parameters

**Interview 3:**

- Not answered

**Interview 4:**

- We are many patients. It is complicated.
- Computer, internet access, knowledge of equipment and programs.
- The specific technological needs and the feeling of being always controlled without having to move from his home.
- Information.
- That they will be taught to use it, he believes it would not be a great difficulty, but her mother gets very nervous with these things and she refuse to learn its use.
- Need for learning, both in terms of technology as well as information about his condition.
- Requirements for use: training course.

**Interview 5:**

-Mainly depends on two factors. Patient involved in the ICT and learning from it. For this reason, needed to ensure the success of the empowerment, simplicity in service exposure and a minimum of autonomy by the patient and/or caregiver and knowledge.

#### **Interview 6:**

Answered with the question: What requirements do patients and informal carers have for PEHP service usability?

### **What requirements do patients and informal carers have for PEHP service content?**

#### **Interview 1:**

In our initial experience we have avoided the complicated monitoring that requires devices attached to the program and send data to it (via Bluetooth or similar) making the patient to enter the data by hand so they have to be easy to get. We have seen that the basics are easy to get for any patient with lower cost (weight, blood pressure, temperature and even saturation of oxygen or glucose). These data are very approximate, and accompanied by specific questions directed to the profile of the person or the pathology complete useful information to the doctor

#### **Interview 2:**

Will we need the health folder?

#### **Interview 3:**

-To know how to put data and how it would control you.

#### **Interview 4:**

- Knowledge
- It would be interesting and it gives that certain patients feel safer
- they do not have to rely on the possibility of mobilizing
- to be informed
- The information has to be explained very clear and this has to be not very complicated.
- Become familiar with ICTs
- Learning. He thing that with patience he can do that

#### **Interview 5:**

-Requires an adequate training and change in the role of performance on these devices. I.e. take decisions according to a single protocol

#### **Interview 6:**

Answered with the next question: What requirements do patients and informal carers have for PEHP service usability?

### **What requirements do patients and informal carers have for PEHP service usability?**

#### **Interview 1:**

As previously mentioned requirements are physical access to technology (must have access to the internet via PC or mobile phone or tablet), that as we have seen is something that is quickly spreading in the population and although much remains to be done can be supplemented with caregivers of all kinds. For a caregiver can also be easier to feed a program of monitoring than have to be attentive to the patient and go to the urgency, queries or even hospitalizations that avoided using this technology.

#### **Interview 2:**

Contact online systems

#### **Interview 3:**

Contact by email, phone system

#### **Interview 4:**

- The systems has to be easy to use
- The patients have to be taught properly

- The systems has to be easy to use
- Older patients and certain carers are not familiar to these technologies.
- It has to be as simplest as possible, especially for elderly patients,
- That it is not complicated.
- The use of specific devices with few buttons.

#### **Interview 5:**

- Must have the degree of autonomy to be able to handle this kind of tools and understanding of the instructions necessary for its management.
- Provide necessary communication systems (telephone, internet).
- At least at the beginning of the programme and to ensure the success of the project, you should select patients at home with easy accessibility.

#### **Interview 6:**

- The data are highly suitable. I don't think you have to add anything else.
- Must know how to use them and training
- Must be adapted to the age, easy-to-use, take into account the cultural level of the patient and caregiver or not is.
- the devices must to be easy to use. The devices must to work well.
- The access to maintenance technicians of the machine has to be quick
- Few changes in routine
- Not is if it would be able to use the new technologies, to control them would have to teach me.
- Training in the device use
- If I have adapted to e-prescriptions it seems to me to be comfortable
- Learning of the use of the machine.
- Quick maintenance system
- Occasionally the machine not detected as the patient is
- Difficulty in learning
- The patient is very aware of the data and worry too much if any data does not come within the parameters.
- Designed questions in the machine are very well.
- The amount of data is well
- They require direct and personalized training.
- One of them is not interested and prefers to continue with the usual controls in the health center.
- No need because he is not going to use it
- He believes that having much attention in training and handling of the equipment it would be easy to use it although he cannot use it because he has problems in his vision, if it was with the phone it would not have any problems.

### **What concerns do patients and informal carers have about PEHP?**

#### **Interview 1:**

They fear the remoteness, coldness and lower follow-up. On the contrary in the survey have found that the patient feels closer to the staff welfare, more aware of his illness. This gives security and sense of control to the patient.

Also do not forget that the use of this route does not eliminate the classic presence systems (consultations, urgency...) issue that we have to leave clear to patients and caregivers.

#### **Interview 2:**

How to query the TM data and possibly not understand them

#### **Interview 3:**

Than us when it comes to information professionals to the best not going to well identify the data

that you send us, because it is not the same being in consultation and to explain it to you or do so via e.mail

#### Interview 4:

- Many patients still prefer the personal attention of the nurse or the doctor.
- There are cases as cures, the general appearance, colour, that cannot be measured with machines.
- Lack of human contact that is essential when we talk about health. Need for knowledge for elderly and vulnerable health
- The management of technologies.
- That you end up having little contact with professionals, less face-to-face attention.
- Whenever there has been a novelty (telephone consultation, consultation administrative, e-prescription...) have had reservations and at the end it was all advantageous.
- He does not worry: what he already knows and uses seems fine and if there is something new he can learn about that. In addition, He can ask help to the family if necessary.

#### Interview 5:

- Self-management and self-care together with the decrease of the face to face consultation can increase the risk of being sick.

#### Interview 6:

- All the data that I measure at home must be reviewed by specialists
- Concerned about the loss of actual physical contact, assessment / exploration of professional physics are concerned about the loss of contact with health professionals.
- I am concerned that with all these new systems we can miss human contact with professionals
- The patient wants to keep coming to the doctor, to speak with the person.
- The machine does not function or remove the machine after a period of time.
- The specialists are not visible to the patient.
- He has no computer or internet at home.
- This is very modern
- Failures in technology.
- That in future all that is done now can be not useful.
- That it is not easy to handle
- The concern that someone in "the other sites" sees the data that are being collected.

### 5.1.2 Puglia pilot site

Type of event: interview or focus group	Focus Group
Date at which the interview / focus group took place	30/04/2013
Venue at which the interview / focus group took place	Campi Salentina District
Duration of the interview / focus group	2 ore
No. of participants in interview / focus group	3 patients and 1 care giver
Type of user groups/stake holders involved	Patients and care givers
Recruitment criteria/rationale applied	Chronic patients involved in the ICCM

## Questions to start the focus group interview with patients and informal carer



**Do you use ICT equipment like computer, smart phones, tablet PCs for private purposes?**

Patients involved in Focusgroup do not use advance technology

**How do you stay in contact with your family and friends? Do you write e-mails and/or make use of social networks like facebook or Twitter? Have tried using services like skype or other video conferencing software?**

Only by phone and mobile

**In general what advantages or disadvantages do you see in using ICT applications?**

Don't use technology but can imagine clearly the utility

**How do you evaluate the healthcare services you are currently receiving (with or without help of ICT)?**

Patients are happy about the chronic care methodology, happy to take part to the decision making process about his/her own condition, but mainly they feel well looked after and uphold

**Do you see any advantages or disadvantages of the way services are currently provided?**

Advantage are more than disadvantage

**Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?**

Patient don't think the services should change/improve, but they think that technology can improve the service

**Could you think of any ICT application or service which might help improving your health status?**

I can't give an answer

**Do you currently make use of healthcare specific ICT e.g. telecare or telehealth equipment/services?**

Patients say that they occasionally underwent telemedicine services

**Can you imagine that CareWell services will address any of your personal need e.g. healthcare related needs?**

Certainly carewell will push the improvement of care delivery

**Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you envisage?**

They hope advantages in terms of introducing technology and more remote monitoring

**Could you think of any factors hampering or facilitating the implementation of CareWell services?**

Advantages:

Less problems in receiving care services and less need to move to go to see doctors

Disadvantages:

Lack of ICT tools on the entire regional territory;

Poor training and education for professionals

**Are you willing to use new ICT in general and/or CareWell services in particular?**

Certainly yes if they improve the current model

## **Patient and informal carer requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)**

**What are the advantages of CareWell Patient Empowerment and Home-support services?**

Less problems for patients and professionals to reach the healthcare delivery centers

**What difficulties do patients and informal carers imagine CareWell Patient Empowerment and Home-support services will bring?**

If well informed there is no problem

**What changes would you have to make if CareWell Patient Empowerment and Home-support services were part of your life?**

Improvement in the management of my pathology

**What needs / expectations do patients and informal carers have for how the Patient Empowerment and Home-support services will work?**

Needs/expectations

More availability of ICT tools /devices . better integrations of team work and feel better looked after

**What functions do patients and informal carers want / need from the Patient Empowerment and Home-support services?**

Improvement of contacts with professionals of the care team interms of quality and quantity of activities carried out

**What needs / expectations do patients and informal carers have for Patient Empowerment and Home-support service content?**

More services available and more efficient thanks to the technologies available.

**What needs / expectations do patients and informal carers have for Patient Empowerment and Home-support service usability?**

Technology easy to use and proper training to use it

**What concerns do patients and informal carers have about Patient Empowerment and Home-support service?**

The feeling of being not able /ready inadeguate towards new technology

### 5.1.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 5.1.4 Veneto pilot site

Type of event: interview or focus group	Interviews
Date at which the interview / focus group took place	April 2014
Venue at which the interview / focus group took place	various
Duration of the interview / focus group	one hour each
No. of participants in interview / focus group	10
Type of user groups/stake holders involved	Patients and Users
Recruitment criteria/rationale applied	Patients responding to the inclusion criteria

The target group of citizens that are foreseen to involve in the project has been defined according to the following characteristics :

- Age over 65 years old;
- Presence of chronic conditions;

- Need of frequent and recurrent care;
- Presence of frailty condition;
- Movement difficulty or impairment.

This cluster of people can be useful divided for the purpose of the questionnaire into two main sub-groups:

- People between 65 and 75 years old;
- People over 75.

These two subgroups present significant differences in terms of capability in the use of technology, with a progressive decrease in relation to the increase of the age.

In fact if the ability to use a mobile phone for making calls is sufficiently spread across all the target group, the advanced usage of smartphones or pcs or tablets is a quite exclusive ability of the citizens in the segment between 65 and 75 years old (with of course some exceptions in the other segment).

These data were also confirmed in the RENEWING HEALTH project in which the 45% patients with similar characteristics declared to be able to use a mobile phone to make a call and only the 6% (mostly concentrated in the age band 65 – 75 years old) declared to be able to use a pc.

The quite restrained incidence on both the categories upon described of people with some ability in the usage of technology is due to two main factors: on one hand the lower education level, especially for the born before the end of the 2nd world war (>70 years old), on the other hand the geographical conditions of the territory served by the ULSS nr.2, typical of the mountainous areas, that has delayed the deployment of the network infrastructure and the broadband connections.

In most of the cases, the caregivers have more and more confidence in the use of technology, especially because they are quite younger than the patients.

Therefore the questions had to be heavily simplified to the target population.

The patients of the home services are quite satisfied of the care they receive from the primary care. They foresee the possibility of an improvement of the cares and their quality of life but at the same time they have to be followed and assisted in the monitoring process. Technology is not seen as an obstacle but it has been stressed the fact that for using it they need to be assisted.

Another aspect that would be taken into account is the fact that in this context a self-monitoring too pushed could be perceived as intrusive and could lead produce more anxiety and concern in the patient than benefits for the quality of life.

## Questions to start the focus group interview with patients and informal carer

### How do you evaluate the healthcare services you are currently receiving (with or without help of ICT)?

The homecare services are commonly defined as good from the patients and their caregivers. The ICT part is not so evident for the recipients of cares.

### Do you see any advantages or disadvantages of the way services are currently provided?

People who receive home care services have complex needs. With this background the services themselves are seen as an advantages.

### Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?

The possibility to receive more services staying at home is seen as a significant improvement.

### Can you imagine that CareWell services will address any of your personal need e.g.

### healthcare related needs?

The professional in charge of the care will be more updated about the conditions of the patients.

### Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you envisage?

The possibility to receive more services staying at home is seen as a significant improvement. Moreover the new services at home is perceive as an increase of their safety.

The usage of technology is a barrier and it is felt very distant from their capabilities.

### Could you think of any factors hampering or facilitating the implementation of CareWell services?

Again technology is felt as a hampering factor. There could be a facilitation if the activities would be assisted by professionals or trained caregivers.

### Are you willing to use new ICT in general and/or CareWell services in particular?

There is a common feeling that these services can be used if assisted by professionals.

## Patient and informal carer requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)

### What are the advantages of CareWell Patient Empowerment and Home-support services?

More control of the health status is perceived as an improvement of quality of life and personal safety.

### What difficulties do patients and informal carers imagine CareWell Patient Empowerment and Home-support services will bring?

Patients alone need to be supported in the monitoring. They feel it as an improvement but at the same time as something very difficult to do by themselves.

### What needs / expectations do patients and informal carers have for Patient Empowerment and Home-support service usability?

Patients feel that the usability of the service could be enhanced by assistance of a professional or a caregiver.

### What concerns do patients and informal carers have about Patient Empowerment and Home-support service?

Need of assistance in the measurements, and in all the phases of the service delivery.

### 5.1.5 Lower Silesia pilot site

Type of event: interview or focus group	meeting
Date at which the interview / focus group took place	4.04.2014
Venue at which the interview / focus group took place	Falkiewicz Hospital
Duration of the interview / focus group	2hrs
No. of participants in interview / focus group	7+8
Type of user groups/stake holders involved	Administration and Clinical users
Recruitment criteria/rationale applied	

### Questions to start the focus group interview with patients and informal carer

**Do you use ICT equipment like computer, smart phones, tablet PCs for private purposes?**

Patients: most of them don't; caretakers: most of them do

**How do you stay in contact with your family and friends? Do you write e-mails and/or make use of social networks like facebook or Twitter? Have tried using services like skype or other video conferencing software?**

Patients: home visits, telephone, skype

**In general what advantages or disadvantages do you see in using ICT applications?**

"I don't have a computer" "I don't know how to use computer" "I'm scared it will not work"; advantages include fast communication without going out

**How do you evaluate the healthcare services you are currently receiving (with or without help of ICT)?**

It takes a lot of time to get in touch with the doctor, doctors have no time, they don't talk about all aspects of my health that I would like to discuss, reaching the hospital to register and for the visit takes a lot of effort and demands a lot of time, lines are long

**Do you see any advantages or disadvantages of the way services are currently provided?**

-in most cases I can be prescribed proper drugs or sent for tests, but I'm not explained enough about the treatment I'm subjected to; when I read newspapers/TV/internet websites about health I don't know what to believe because information vary

**Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?**

yes

**Could you think of any ICT application or service which might help improving your health status?**

I would like to be well informed about what to do and what not to do, how to change my diet or what supplementary treatment could help me, I would like to obtain this information written somewhere or reported to my caretaker not to forget it

**Do you currently make use of healthcare specific ICT e.g. telecare or telehealth equipment/services?**

no

**Can you imagine that CareWell services will address any of your personal need e.g. healthcare related needs?**

yes

**Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you envisage?**

It will be difficult to learn how to use it but it will be beneficial for my health and information

**Could you think of any factors hampering or facilitating the implementation of CareWell services?**

It will be easier for me if my family members or caretaker could have insight into it and be trained how to use it

**Are you willing to use new ICT in general and/or CareWell services in particular?**

yes

## **Patient and informal carer requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)**

**What are the advantages of CareWell Patient Empowerment and Home-support services?**

Better and faster communication with health professionals, better guidance in organizing lifestyle to help improve health

**What difficulties do patients and informal carers imagine CareWell Patient Empowerment and Home-support services will bring?**

Use of online service

**What changes would you have to make if CareWell Patient Empowerment and Home-support services were part of your life?**

Learn to use computer

**What needs / expectations do patients and informal carers have for how the Patient Empowerment and Home-support services will work?**

- thorough introduction and guidance about how to use the system
- health professionals not failing to communicate with patients on daily basis

**What functions do patients and informal carers want / need from the Patient Empowerment and Home-support services?**

Better quality of information management, easier regular communication, online registrations, possibility to call the doctor

**What needs / expectations do patients and informal carers have for Patient Empowerment and Home-support service content?**

Written advices from the doctor, reliable healthy lifestyle guide

**What needs / expectations do patients and informal carers have for Patient Empowerment and Home-support service usability?**

Ease of use

**What concerns do patients and informal carers have about Patient Empowerment and Home-support service?**

That it will not work, work slowly, that the doctors will not be answering, that it will be difficult to use or that they will commit some negligence unwillingly

### 5.1.6 Croatian pilot site

The Croatian pilot site decided to conduct separate focus groups. One with patients and a second one with informal carers.

#### Patient focus group

Type of event: interview or focus group	Focus Group
Date at which the interview / focus group took place	March 27 <sup>th</sup> , 2014
Venue at which the interview / focus group took place	Puls – public opinion research agency Budmanijeva 1, Zagreb
Duration of the interview / focus group	2h
No. of participants in interview / focus group	5
Type of user groups/stake holders involved	Patients
Recruitment criteria/rationale applied	65+ YOA, chronic patients

**Do you use ICT equipment like computer, smart phones, tablet PCs for private purposes?**

In most cases elderly patients (65+) do not use ICT. However, one lady said that she is retired but still active so she is using the PC daily, mostly for sending emails.

**What do you see as the main benefit you get from using ICT?**

The greatest advantage they see is having access to internet and being able to get information that usually would not be available if you were not using ICT.

**Have you ever used ICT to seek medical advice online, or have you asked your friend/family to look it up for you?**

Since just one lady was actively using PC she was the only one that was searching medical info online. Others have been relying on their informal caregivers to seek that type of info. Some of the patients even communicated with their doctors using email – mostly indirectly getting the help from caregivers.

**Do you think that ICT technology, such as applications for mobile phones and tablets connected to internet, could help you manage your disease?**

Most patients would like to be able to access internet and seek medical advice, they even give example of some friend and neighbours that were quite successful in getting medical info from internet and then verifying it with their GPs. However, all of them say that they would not like to lose the physical contact with doctor, so ICT is ok but only as supplement to the standard GP services, not as replacement.

**How often do you visit your GP in his/her office?**

According to the need, some problems can be solved even by phone (such as getting the recipe by phone, for standard therapy only). Generally, they see the doctor in the office at least once a month or when they have some acute problem.

**How do you travel to his/her office?**

In some cases on foot, if the office is close and patient can walk, but in most cases by taxi or public transportation.

**Does your GP provide you with info or education about your disease or other health related topics of your interest?**

Yes they teach us about our disease, what can happen if we do not stick to the therapy and medications, about healthy nutrition, regular exercises. However, doctors do not have enough time to educate you in more details; this is usually done by field nurses during field visit to patient's house.

**Do you always comply with doctor's advice?**

Most of them keep up with what the doctor said, but when they are at parties or have a birthday they do eat some food that was advised not to be eaten. They are also very precise when taking medications according to what doctor said.

**How are your informal caregivers involved in helping you to keep with doctor's advice?**

Most patients have some friend or family to take care of them, cook a meal or clean the house for them. Their informal caregivers help them with preparing pills for the whole week; they use the pill boxes for planning daily doses.

**Do you measure your blood pressure or sugar levels regularly? Do you keep track of your measurements?**

Diabetes patients keep their log book and then they take it to GP or specialist when they go for office visit. Same for patients with low blood pressure, they also keep logbook.

**Are you practicing any kind of physical activities regularly?**

In most cases the either take easy walks or practice house work as physical activities. Some are riding bicycles or working in garden – they are advised by doctors to stay active so they tend to comply with that advice.

**Informal carers focus group**

Type of event: interview or focus group	Focus Group
Date at which the interview / focus group took place	April 3 <sup>rd</sup> , 2014
Venue at which the interview / focus group took place	Puls – public opinion research agency Budmanijeva 1, Zagreb
Duration of the interview / focus group	2,5h
No. of participants in interview / focus group	8
Type of user groups/stake holders involved	Caregivers

Recruitment criteria/rationale applied

Taking care of 65+ YOA chronic patients.

### Do you use ICT equipment like computer, smart phones, tablet PCs for private purposes?

Most of them use some kind of devices for internet access.

### Do you use ICT equipment to get info about diseases burdening the people you take care of?

They do, but they generally more rely on doctors' advice. They usually seek medication side effects online. It would be great if they could have online access to info on all medications their patient is taking.

### Do you think you could take better care of your patients in case you had some kind of ICT technology for healthcare?

They all agree it would help them as caregivers a lot. They could easily get medical feedback and adjust the medications according to the feedback from doctor – they would not have to absent from work as much and could still monitor their patients. Some are giving example of remote patient monitoring for cardiac patients that they heard of – some friend are getting such service in Germany and they like the idea of having ECG in their home.

### Have you ever taken part in some kind of healthcare education programmes?

Most of them did not because there is nothing for them; usually it is organized for pregnant women and young mothers. But they would like to get more info and be educated.

### Do you have field nurse visiting your patient?

One caregiver does have a field nurse coming to the house to visit patient.

### What do they do during the home visit?

They take care of prevention and education; take some measurements on blood pressure and sugar and even some social care activities. They also educate the caregivers and tell them what the patient's status is, and what should be done to improve it.

### What is your biggest concern or obstacle when helping your patients – what kind of assistance would help you most?

As biggest obstacles they mention shortage of free time (cannot get out of job (sick leave) to help family), hard to get the contact to GP or nurse to get some medical advice, hard to get info or educational materials – they would like to have such data easily available and organized for their specific need. In the end they all agree that also very important aspect is psychological help and support – they need to get trained how to live with and mentally help patients but also themselves.

## Requirements for patients and informal caregivers

Technology/functionality related requirements	Service process related requirements	Other requirements
Enable patients and caregivers to access patient's medical data that was collected during the field nurse visit.	Define specific time window that can be used for field nurse communication with patients.	
Educational tool for caregivers and patients – make educational materials, available for review even after the nurse has left patients home. Education should cover disease info, therapy and medications side effects, nutrition and exercises.	Define process for in house visits that will include specific type of psychological support to patients and caregivers.	



## 5.2 INTEGRATED CARE COORDINATION PATHWAY (ICCP) REQUIREMENTS

### 5.2.1 Basque Country pilot site

The Basque Country Pilot assessed the nature of their service components for the ICCP pathway and came to the conclusion that patient and informal carer requirements should also be gathered for this pathway, as well as for the PEHP pathway.

#### Interview 1:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	September/November 2013
Venue at which the interview / focus group took place	Clínica Asunción
Duration of the interview / focus group	Monitoring patients during 3 months
No. of participants in interview / focus group	6 interviews
Type of user groups/stake holders involved	Patients with chronic diseases
Recruitment criteria/rationale applied	Chronic pathology and possibility to Access to the programme (Web in PC o Smartphone)

#### Interview 2:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	
Venue at which the interview / focus group took place	Gros (Guipúzcoa)
Duration of the interview / focus group	
No. of participants in interview / focus group	
Type of user groups/stake holders involved	
Recruitment criteria/rationale applied	

#### Interview 3:

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	March 2013
Venue at which the interview / focus group took place	Guipúzcoa
Duration of the interview / focus group	
No. of participants in interview / focus group	1
Type of user groups/stake holders involved	Relative
Recruitment criteria/rationale applied	Chronic patient 's relative

#### Interview 4:

Type of event: interview or focus group	Interviews
Date at which the interview / focus group took place	27 march- 2 April



Venue at which the interview / focus group took place	Comarca Uribe
Duration of the interview / focus group	30 minutes
No. of participants in interview / focus group	8
Type of user groups/stake holders involved	Patients and careers
Recruitment criteria/rationale applied	Plurypathology

**Interview 5:**

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	31 March- 3 april
Venue at which the interview / focus group took place	Hospitalization and external consultation
Duration of the interview / focus group	30minutes/patient ( 270 minutes )
No. of participants in interview / focus group	9
Type of user groups/stake holders involved	3 physicians
Recruitment criteria/rationale applied	Plurypathology and complex chronic patient

**Interview 6:**

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	31 march-3 april
Venue at which the interview / focus group took place	Home and hospital
Duration of the interview / focus group	30 minutes
No. of participants in interview / focus group	4 patients in primary care + 4 patients in hospital 2 careers in primary care + 3 careers in Hospital
Type of user groups/stake holders involved	EGC, EE, Nurse of primary care, doctor of primary care and physician
Recruitment criteria/rationale applied	Pluripathology patient ( 4) and patients using TM ( 2 in primary care)

## Patient and informal carer requirements for CareWell Integrated Care Coordination Pathway (ICCP)?

### What are the advantages of CareWell ICCP?

**Interview 1:**

The patient is included in the concept of integration and continuity of care that is giving with this route. The advantages that this involves:

- Increase the efficiency of care avoiding the duplication of efforts and reducing workload and cost.
- Increase the patient/user satisfaction and their trust in the system, since the patient feels that is attended in a continuous manner

-It increases the security of the system, reducing the risk of errors.

**Interview 2:**

- Reduce the outpatient visits.

**Interview 3:**

- decrease the number of revenue made by our mother.

**Interview 4:**

-Each professional will know the activities of other specialists to avoid repetition.

-The displacement of older persons with much pathology borders them fairly and in this way they need less displacement. This route (not face to face consultation, e-prescriptions...) benefits to the caregiver saving time required. E-prescribing system seems great and fast, because it does not need to go through the health center and goes directly to the pharmacy. It has also gained in agility and save time with telephone consultation for questions or questions that do not require the presence of the patient in the query.

-Not having to walk to one side and another with papers. The recipes control is better since operates the electronic prescription. Saving in diagnostic tests (analysis...), the patients can ask me about them, although these analysis have been requested by specialists.

-All advantages. Not moves unnecessarily, and we can call from house to ask for for analysis, problems , recipes. When the patient goes to consultation, the physician knows what the specialists have said or done. It seems incredible.

-Above all convenience, saving time for professionals and family.

-She feels safer and more wrapped.

-Facilities for professionals

-Patient safety

-Comfort for the patient/caregiver.

**Interview 5:**

-Improves the patient's care: the different specialists know all the information, avoid duplication, coordination of agendas avoiding unnecessary travels for the patients.

**Interview 6:**

-not having to be talking always the same, and sometimes we don't know how to explain well. Better quality of care with the professional coordination (Primary care-Secondary care). They feel that he prevents them to be the only professionals that have to explain what happens in hospital, and they can explain with his primary care physician, and his nurse... or we have not understood the instructions that give us to tell another doctor or nurse

-Greater security

-It is fine for them. As more professionals are committed, better the care will be

-It is very adequate for the patient since with this route the patient is more slope and more controlled.

-I think it will not have many problems.

-It is faster and more efficient to save time. They also appreciate that professionals in both areas can communicate quickly to manage questions diagnostic, treatment or other. It saves time and more comfort and prevents displacement.

-Improved follow-up of the patient (caretaker)

-When you go to the emergency room all the data is in the computer (caretaker)

-The electronic prescription avoids unnecessary travels to the health center and moreover the patients and caregivers believe that confusion is avoided. Another patient believes that with the electronic prescription you lost contact with the nurse and the Center.

**What difficulties do patients and informal carers imagine CareWell ICCP will bring?**

**Interview 1:**

- The technology management and the environment that the must access to manage their health information.

**Interview 2:**

-I think that any

**Interview 3:**

-Any difficulty

**Interview 4:**

-The implementation requires to mentally prepare to patients and to the health professionals.

-Do not see difficulties in this coordination path while the response is quick and the solution appropriate to each time. This path facilitates the work.

-Only know the route, as we work now on the subject of prescriptions, non-face to face consultation.... But they have become accustomed soon and they only see advantages.

-Any difficulty.

-It is required always a shoot to make it work well.

-No

-No

-Do not encounter any difficulties, sees only advantages

**Interview 5:**

- The limitation can be that perhaps that there is no a real coordination.

**Interview 6:**

-I don't think that we will have too many problems. Perhaps it is difficult to contact the different specialists.

-Believes that not because the aid is good and positive

-Elderly people who do not know how to use properly the ICTs. Regarding to ICTs, the patients appreciate them but they don't have handling, except their caregivers can used them.

-Can confuse the patient/caregiver

-Do not see real problems except, perhaps the personal barriers when involving in the project.

-Not have computer or internet at home

-You lost the contact with the doctor - patient (caretaker)

-Problems of communication between professionals that can affect the patient (caretaker)

-In a situation of gravity that the system does not capture the situation (caretaker)

### What changes would you have to make if CareWell ICCP was part of your life?

**Interview 1:**

Those that the changes asked to me. In the case of the coordination path the change are few as for example in the case of the e-prescribing to go to pharmacy to provide me the drug.

**Interview 2:**

- Any

**Interview 3:**

-It has not brought any change on our part.

**Interview 4:**

-We will have to go to less consultation, and no longer for recipes.

-None

-Already part and is no problem, nor is the need for change

-The changes will result in greater comfort.

-Only to assimilate the changes of the new forms of care and. He has taken it well. Thinking about older people he thinks that it will be more difficult for them to assimilate these new routes.

-Do not have to make any changes. Greater comfort.

-He believes that he has not done or he does not have to make changes.

### Interview 5:

-It is needed to change acquired behaviors: reduce the number of visits to the specialist without decreasing the quality of care, attend to the pharmacy instead to the primary care for chronic treatments.

### Interview 6:

-Perhaps the patients would have to go less to the emergency room and call our doctor when we started to feel bad. To be more in touch with my doctor and nurse when I feel bad since they are those who most know about me and also have the possibility to consult with other specialists.

-When I get my illness worse, before using another service I would have to call to primary care doctor.

-We have to adapt to the new way of professionals working

-One of the patients said that if the coordination path works, the use of the emergency room should be avoid.

-No changes must have developed. If he can call directly to the specialist who has seen him in the Hospital and who knows his illness he could avoid going to his doctor and the emergency room.

-They are new changes which is not yet known how will affect

-Adaptation to the e-prescriptions without problems

-The e-prescribing improves the management of the recipes with dates, not accumulation of recipes and not accumulation of medications at home.(caregiver)

-Adaptation to the new systems (caregiver) by the patient and the family

## What requirements do patients and informal carers have for ICCP functionalities?

### Interview 1:

The patient is not affect excessively since what it does is provide more information passively, and which the patient access if want to access to the clinic history, composed by the system allows to see.

### Interview 2:

-At the beginning any, only if a change in dose medications is required.

### Interview 3:

- A good coordination between hospital and primary care.

### Interview 4:

- Proper coordination and understanding between the professionals.

- That all the information is correctly protocolized and clear

- Good communication between professionals.

- It is required to make an investment in telecommunications and information technologies and also it is required and teach in order to have very integrated teams which are agree on so many things.

- Good personal communication because people communicate worse by phone.

- Thepatients need health center calls are answered more quickly, sometimes called repeatedly without getting to communicate. Currently online citation system seems excellent, but it is require to have a minimal computer and technology knowledge that this patient, for example, does not have.

-Learning and adaptation to the mechanics of this new form of assistance. It is required that the government let also cut spending on health.

-To make it work is important to explained to the patient and to the careers clearly the operation way.

### Interview 5:

-Fast, safe and reliable information systems.

-Confidence between different specialists.

### Interview 6:

- Sometimes there are differences in criteria between different professionals
- Devices, phones, computers should be adapted
- Do not think there are problems, rather all advantages
- A patient and a caregiver express concern because you rush into excess that remain at home when they are ill.
- Another patient says he believes that it will reduce their access to specialized care.
- A caregiver is concerned that his family resides on a rotating basis at different homes in different regions and he does not how it can be affected.
- Repeated fear the loss of direct interaction with professionals of health.
- Non-response to the urgent care
- Loss of contact doctor – patient (caregiver)
- Problems in urgent care (caregiver)

### What concerns do patients and informal carers have about ICCP?

#### Interview 1:

The problem will begin to the route is not implanted, especially in elderly patients with chronic diseases they can see this access as right and the health care system does not provide it.

#### Interview 2:

-I think that any

#### Interview 3:

-I do not think that we have no problem

#### Interview 4:

- If it works well, none
- If it doesn't work, the problem can be data without checking and patients unattended.
- No problems
- None.
- I see only advantages and I don't see problems.
- No problems except if the technology fails. More advantages than disadvantages.
- At the beginning: problems of learning, ignorance of the operation, but how other changes have been learned previously.
- No problems with this form of work. The e-prescribing help a lot to him and avoid unnecessary visits to the primary care center.

#### Interview 5:

- The patients may have the feeling of loss of opportunity comparing to face-to-face consultations.
- Loss in the doctor/patient relationship.

#### Interview 6:

- The healthcare professionals should talk more between them and have into account the opinion of the patient a little more
- Loss in the doctor/patient relationship
- Easy access to the responsible doctors and nurses
- Quick and effective response to the problems
- That there is a good coordination between professionals
- A good communication between professionals(caregiver)



## 6 ORGANISATIONAL AND FINANCIAL REQUIREMENTS

Key organisational and financial requirements were gathered through interviews and focus groups in order to learn more about the organisational and financial needs regarding the development and implementation of CareWell pathways. In contrast to the requirements gathering exercises for healthcare professionals and patients and informal carers the organisational and financial requirements interviews and focus groups didn't seek to gather the needs of users of the service but the organisational and financial elements which need to be considered for the future service to function well. This exercise of requirements gathering is to prepare the sites not only for the design of organisational models in WP3 but for the testing and operation of the pilot services in WP5 and WP6.

### 6.1.1 Basque Country pilot site

Type of event: interview or focus group	Focus Group 1
Date at which the interview / focus group took place	02/04/2014
Venue at which the interview / focus group took place	Primary Care center
Duration of the interview / focus group	1h
No. of participants in interview / focus group	7
Type of user groups/stake holders involved	Management team, healthcare professionals
Recruitment criteria/rationale applied	Management team

Type of event: interview or focus group	Focus group 2
Date at which the interview / focus group took place	2/4/14
Venue at which the interview / focus group took place	Hospital
Duration of the interview / focus group	2 horas
No. of participants in interview / focus group	4
Type of user groups/stake holders involved	Head of Service of Internal Medicine, Section Chief of Internal Medicine, internists
Recruitment criteria/rationale applied	Participants in the project

Type of event: interview or focus group	Interviews 1 (answers are homogenized)
Date at which the interview / focus group took place	2-3/04
Venue at which the interview / focus group took place	Hospital, primary care
Duration of the interview / focus group	20 min
No. of participants in interview / focus group	3
Type of user groups/stake holders involved	2 managers and project manager



Recruitment criteria/rationale applied	
Type of event: interview or focus group	Interviews 2
Date at which the interview / focus group took place	01/04
Venue at which the interview / focus group took place	Primary Care center
Duration of the interview / focus group	2 h
No. of participants in interview / focus group	3 healthcare professionals
Type of user groups/stake holders involved	Clinicians and nurses
Recruitment criteria/rationale applied	Experience in management of frail elderlies

## Questions to start the focus group interview with key experts

### What do you think of the services which are currently provided to patients (with or without help of ICT)?

#### Focus group 1:

We are very interventionist. The service portfolio is extensive but the coordination between healthcare professionals is still poor, interfaces have to be improved. Lack of a comprehensive and integrated view of the patient.

#### Focus group 2:

our Health System is good; however there is room for improvement with the use of ICT tools.

#### Interviews 1:

- Although the care of these patients has improved with better coordination among professionals and the use of improved technological tools, there are still areas for improvement in both areas.
- There are lots of barriers that have to be overcome.
- Significant improvement in terms of accessibility and the use of diagnostic tools.

#### Interviews 2:

Good quality and patient-oriented, but the challenge of fragmented care has to be overcome, especially in complex patients requiring multidisciplinary care. We must direct our efforts towards service integration to ensure a continuum of care that benefits citizen, patients, professionals and healthcare and social services. Thus, society in general.

In this context, ICTs are an essential for communication and information exchange between professionals, but also among professionals and patients

### How do you evaluate the services which are currently provided to patients (with or without help of ICT)?

#### Focus group 1:

use of healthcare indicators. We have tools to obtain lots of healthcare indicators and assess the

results; however, we lack tools to measure economic impact. Our funding is captive and different from that of the hospitals.

### **Focus group 2:**

Improvable. A good service is provided but with a poor development of ICT tools.

### **Interviews 1:**

- The evaluation is performed by means of indicators of both monitoring processes and outcomes, especially in readmissions.
- The assessment so far is positive with good process indicators but perhaps expected health outcomes are more complicated and more time is needed.
- The assessment through meetings and effectiveness of pathways agreed with healthcare organizations.

## **Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?**

### **Focus group 1:**

yes. The patient should be the central axis of healthcare activities and the coordination within Primary Care and, between Primary Care and other actors (secondary care, social care and community care) has to be improved.

### **Focus group 2:**

yes, fundamentally in specific levels of action (patients, coordination between healthcare professionals...)

### **Interviews 1:**

- Some aspects need to be improved, such as the identification of patient, in order to be faster in all healthcare levels.
- Streamline even further the relationship between all healthcare levels and social resources.
- Accessibility to scheduled admissions
- Non face-to-face meetings with Internal Medicine representatives.
- Everything can be improved; we have started working on the pathways and the comprehensive view of the needs. We cannot mark patients properly in our systems at different levels of care. EHR is not fully shared between healthcare professionals.

### **Interviews 2:**

It is necessary to continue introducing improvement actions. Designing care pathways and settling the improvements made. Collaborate with both the social and community care in a systematic way. It is essential to agree on how to use the computerized clinical tool, as well as the communication flow between professionals and, patients and professionals. Introduce ICTs as a tool in our organizational model without losing the purpose of providing services.

## **In which healthcare context do you think ICT applications e.g. telecare or telehealth equipment/services could be used best?**

### Focus group 1:

in all setting related to healthcare professionals and organizations; communication with patients. On the other hand, no evidence exists demonstrating that the telemonitoring is positive.

### Focus group 2:

the telemonitoring has to be directed to specific patients (high risk patients, dependant patients...), in order to ensure the added value of the implementation of the telemonitoring. Other ICT tools (EHR, non-face-to-face consultations, messaging...) can be useful for a broader profile of patients.

### Interviews 1:

- In all contexts. Agreements for the use ICTs are necessary
- The main goal is to try professionals move around the patient and not the patient about the professionals.

### Interviews 2:

In the context of the communication between healthcare professionals (primary and secondary care) and social workers in order to facilitate the exchange of information and improve coordination.

The communication of the patient and/or caregiver with healthcare professional in ways that do not require moving the patient to the health center, to control symptoms, to change treatment, etc... Patients will access to their clinical data when they are outside of their region and require health care.

ICT applications also will be useful for patient training and empowerment, patients will know more about their pathologies, symptoms detection... and for monitoring patients at home.

### From an organisational and financial perspective do you see any advantages or disadvantages in applying ICT for healthcare purposes?

#### Focus group 1:

ICT applications are enablers to improve coordination and communication. However, we have to be very prudent and analyze studies on the efficiency of the implementation of telemonitoring services.

#### Focus group 2:

it is demonstrated that the use of the ICTs is efficient from the economic and organizational perspective, if the use of ICTs is well integrated.

#### Interviews 1:

- The advantages are clear about the speed in the interrelation between professionals and users, which allows a more efficient performance.
- It is necessary to share common and realistic health objectives that are assumed by all professionals.
- Disadvantages: sometimes the use of ICTs slows down the development of projects and they are not tailored to the needs of users. Economic aspects are also considered



disadvantages.

- Advantages: all related to patient empowerment and the better access to both health services and professionals.

### Interviews 2:

The introduction of ICTs is positive if ICTs are considered tools to reach health objectives and if the organizational model is given the priority.

Communication and exchange of clinical information between health and social professionals, in addition to improving patient care, are the priority, and avoid inefficiencies in the health service (duplications of tests and treatments, unnecessary transfers of patients to health centers ...).

The same is applied to the communication with the patient (non face-to-face consultations, follow-up through telemonitoring, anticipation of exacerbations and avoidable hospitalizations ...)

### Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?

#### Focus group 1:

Carewell services favor coordination, communication and patient management. Favorece la coordinación, la comunicación, la autogestión del paciente. There is also the risk of excessive depersonalization; must find a balance between technology and clinical judgment.

#### Focus group 2:

Advantages over all the health system actors (patients, management team, health professionals ...) quality of care, coordination, organizational improvement, economic control .

Disadvantages: resistance to change, poorly developed programs in some areas, need for training and behavioral changes, etc...

### Interviews 1:

- Carewell defines the target population, helps the consolidation of the existing pathway and facilitates de implementation of existing ICTs.
- Advantage: consolidation of the strategy in management of chronic patients, definition of pathways and technological tools.

### Interviews 2:

Advantages of the introduction of ICT:

- Continuity of care
- Complete view of the care process which improves and streamlines care and avoid duplication of tests
- Patient Safety: legibility of therapeutic and care-related documentation
- Efficient management of health professionals
- Patient access to their clinical data
- Patient involvement in their health status

Disadvantages of the introduction of ICTs:

- Reliance on information and communication systems
- Obsolescence of the equipment
- Essential information systematization
- Influence on the organizational flow of clinical care.

### Could you think of any factors hampering or facilitating the implementation of CareWell services?

#### Focus group 1:

The economic factor, the availability of technological media, knowledge of use by the population and the resistance to change of professionals and patients hamper implementation.

The ease of use, accessibility and appropriate training, facilitate implementation, as well as the way of informing people on new technologies and their profits.

#### Focus group 2:

Most of them has to do with the disadvantages: poor training, high economic investment, programs not proven in health systems...

#### Interviews 1:

The rigidity in the way of work of professionals and patients.

It would be easier if the applicability of implemented ICTs would not involve difficulties and if would show improvements fast comparing to the usual care.

The ongoing dissemination and encouragement of involvement in the process are required (incentives for example)

The change of professionals' vision of patient and the methodology of practice could be considered obstacles.

#### Interviews 2:

Factors that hamper:

- Skills and attitudes of professionals
- Professionals' resistance to change
- Investment in technology resources

Enabling factors:

- systematic and sustained training of professionals
- proper explanation of the benefits of the instruments are introduced.

### Do you see potentials for improving the envisaged CareWell services?

#### Focus group 1:

yes, we are working on that direction although still a long way to go.

#### Focus group 2:

yes, if we are gradually overcoming the disadvantages, especially if we are able to engage healthcare professionals in a purposeful way.

#### Interviews 1:

yes, because of the systematization and the impetus to new services.

#### Interviews 2:

the challenge is the systematization and consolidation of all tools.

## 6.1.2 Puglia pilot site

Type of event: interview or focus group	Focus Group
Date at which the interview / focus group took place	30/04/2013
Venue at which the interview / focus group took place	Distretto SocioSanitario di Campi Salentina
Duration of the interview / focus group	2 ore
No. of participants in interview / focus group	n. 9
Type of user groups/stake holders involved	Nurse coordinators, GPs, social workers, primary care management, managing directors of health/social district
Recruitment criteria/rationale applied	Responsible of organizational models and changing management processes in ICCM

### Questions to start the focus group interview with key experts

#### What do you think of the services which are currently provided to patients (with or without help of ICT)?

Services currently guaranteed to chronic patients answer to patients expressed needs, make possible disease and care management and continuity of care.

#### How do you evaluate the services which are currently provided to patients (with or without help of ICT)?

Positively considering the limited technological ,organizational resources

#### Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?

No, but needs to be integrated with the introduction of more ICT tools and training

#### In which healthcare context do you think ICT applications e.g. telecare or telehealth equipment/services could be used best?

In specifica areas of the Region such as mountainis, islands and also to support home care for elderly, frail and disable patients

#### From an organisational and financial perspective do you see any advantages or disadvantages in applying ICT for healthcare purposes?

Advantages: Reduce costs avoiding repetitions of tests and medical check up already performed avoiding waste of economic resources

Disadvantages: More investement in economic and human resources

#### Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?

Advantages:

- patients doesn't need to go to the clinics or GPs surgery
- Avoid booking tests and medical check up; Reduction of waiting lists

Disadvantages:

- Lack of technology on all regional territory (not omogeneous distribution)
- Poor training of professionals

#### Could you think of any factors hampering or facilitating the implementation of CareWell services?

Difficult interaction among the professionals and the patiens often is very diffident and not

particularly happy to talk about himself his condition and needs above all in little villages (cultural problem)

#### **Do you see potentials for improving the envisaged CareWell services?**

Possible improvement can be done in monitoring patients also by sharing updated patients data and information in real time

### 6.1.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 6.1.4 Veneto pilot site

## **Questions to start the focus group interview with key experts**

#### **What do you think of the services which are currently provided to patients (with or without help of ICT)?**

The services seems to be well organized and appreciated by the patients.

#### **How do you evaluate the services which are currently provided to patients (with or without help of ICT)?**

Services are quite good at the present time. There are skilled professionals who deliver care following different procedures for the different burdens of needs of the patients, from the simple ward assistance to the nurse home service to the more complex personalized integrated care plan. The services have been evaluated from time to time with a customer satisfaction questionnaire that has always given high scores of appreciation.

#### **Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?**

In order to further improve and further integrate the services delivered to the citizens and patients it should be used new instruments to go beyond the actual compartmentalisation of the services (that are provided by the only organization in charge of all the aspect related to the health and social care: the Local Social and Health Authority).

#### **In which healthcare context do you think ICT applications e.g. telecare or telehealth equipment/services could be used best?**

The telecare / telehealth can have their best applications in the context of the management of chronic conditions especially in those patients who are impaired or for which it can result difficult to get to the hospital. Those kinds of patients are already served by the primary care's home care service but the telemedicine could perhaps bring new services that in the current condition cannot be delivered (advice or consultations from specialists, exams that require a an assessment by a specialist). Moreover, a platform that will allow an integrated view of the conditions and the services delivered to a patient could be the proper solution to the compartmentalisation of the services described above.

#### **From an organisational and financial perspective do you see any advantages or disadvantages in applying ICT for healthcare purposes?**

#### **Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?**

There are many advantages: the first will be the support for a better coordination of all the services that deliver cares to the patients. Moreover a unique platform will allow to consult all the data about the services from the same system, reducing the fragmentation of the informations inside

the LHA.

From a financial perspective is expected a reduction of the costs keeping patients at home and bringing to them services that otherwise they could receive only by coming to the hospital for an outpatient visit or a hospitalization.

A disadvantage could be the possible high costs of technology at the beginning or the resistance to change of some professionals within the organization that are used work following well established procedures.

#### Could you think of any factors hampering or facilitating the implementation of CareWell services?

From the organizational point of view the resistance to change and to technology can be two factors that can hamper the process of deployment and has to be take into account.

### 6.1.5 Lower Silesia pilot site

Type of event: interview or focus group	meeting
Date at which the interview / focus group took place	4.04.2014
Venue at which the interview / focus group took place	Falkiewicz Hospital
Duration of the interview / focus group	2hrs
No. of participants in interview / focus group	7
Type of user groups/stake holders involved	Administration and Clinical users
Recruitment criteria/rationale applied	

### Questions to start the focus group interview with key experts

#### What do you think of the services which are currently provided to patients (with or without help of ICT)?

They are not satisfactory, patients are not informed as well as they should be. They don't understand the link between different types of ailments they have (e.g. that fungi infection may have its roots in wrong dietary habits, and result in general weakening of immune system and susceptibility to bacterial or viral infections)

#### How do you evaluate the services which are currently provided to patients (with or without help of ICT)?

The services are not satisfactory.

#### Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?

There is a need for improvement. Better information system based on online platform for communication could help to improve the situation. Longer time designated for the patients visit in doctor's cabinet will help to solve a lot of problems with returning patients.

#### In which healthcare context do you think ICT applications e.g. telecare or telehealth equipment/services could be used best?

In communication between patient and doctor (especially regarding the patient's current treatment).

#### From an organisational and financial perspective do you see any advantages or disadvantages in applying ICT for healthcare purposes?

The application will be costly and time consuming, it will be needed to upgrade computers in the hospital and get some new for patient's use, time and money will need to be spent on personnel's training. After implementation patients and healthcare providers will benefit from the services: patients will not have to come to the hospital to consult their basic questions and doctors will have more time for other patients; there will be no need for patient to come to pick their results personally from the hospital but they will be delivered online. Lines in the hospital will be shorter and functioning of it will be faster and more efficient.

#### Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?

Advantages include: easy access to the treatment data or results of tests whenever patients want, simple way to communicate with healthcare providers, patients don't have to come to the hospital to pick their results or consult easy questions, more general and integrated view on health will be provided to the patient (explaining necessity to eat healthy, be active physically and mentally, maintain beneficial emotional state)

Disadvantages: it will be difficult for the elderly to switch to online system

#### Could you think of any factors hampering or facilitating the implementation of CareWell services?

To facilitate the implementation patients should be well informed about the ITC and be sure that the access to their data is confidential; the problem with some of the patients can be that they are not able to use complicated on-line systems or don't have computers- this could be solved by informing them that a health provider can introduce them to the system and that they can use specially designated computers in the hospital.

#### Do you see potentials for improving the envisaged CareWell services?

They will be improved gradually based on emerging problems or ideas.

### 6.1.6 Croatian pilot site

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	March 20th, 2014 April 1st, 2014 April 10th, 2014
Venue at which the interview / focus group took place	Zagreb healthcare centres (Tuškanac 23, Bartola Kašića 6, Kruga 44)
Duration of the interview / focus group	1h
No. of participants in interview / focus group	2
Type of user groups/stake holders involved	Doctors
Recruitment criteria/rationale applied	Doctors that will be taking part in CareWell project.

## Questions to start the focus group interview with key experts

#### What do you think of the services which are currently provided to patients (with or without help of ICT)?

Healthcare services for chronic patients are not provided in a strictly structured way, so further enhancements could come from structuring the field nurse service on all levels – daily work routines of field nurses, communication and information sharing between medical professionals involved in patient treatment as well as education of patients and their caregivers. In that way the same quality of healthcare service will be provided to all patients regardless of which medical team

is taking care of the patient..

**Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?**

It would benefit patients a lot if healthcare professionals were given ICT tools that would help them share the patient info and provide better education about their disease.

**In which healthcare context do you think ICT applications e.g. telecare or Telehealth equipment/services could be used best?**

Sharing of patient medical data for better collaboration of healthcare professionals, education and healthcare related content sharing as well as patient empowerment and remote monitoring/management of chronic disease management. Another interesting niche are rural healthcare services where healthcare teams could deliver healthcare services to underserved population.

**From an organisational and financial perspective do you see any advantages or disadvantages in applying ICT for healthcare purposes?**

Providing better education to chronic patients will definitely decrease the number of hospitalizations caused by improper lifestyle and not being compliant to medications therapy prescribed by GP or specialist. Lower number of hospitalizations will result in lower cost of chronic patient treatment. On the organizational side, it will allow medical teams to provide better quality healthcare service to the greater number of patients but still keeping the same or even lower cost to the healthcare system.

**Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?**

Better communication and information sharing between healthcare professionals involved in treating patient as well as advanced educational methods powered by ICT tools are obvious advantages for healthcare system. Finally, implementing new processes in managing chronic patients or adopting/improving the existing processes will provide even greater advantage to healthcare system.

**Could you think of any factors hampering or facilitating the implementation of CareWell services?**

We will need to provide technical support to both medical teams, using the new technology for communication/info sharing, as well as to the patients that will be using ICT tools for accessing the medical content and educational materials after the field nurse has left their home. Arranging the quality technical support to all stakeholders will help us overcome all challenges in implementing CareWell services.

**Do you see potentials for improving the envisaged CareWell services?**

Not at the moment, perhaps some fresh ideas might come up during the operational part of the project, when we see how it works in everyday work.

## 6.2 INTEGRATED CARE COORDINATION PATHWAY (ICCP) REQUIREMENTS

### 6.2.1 Basque Country pilot site

#### Organisational and financial requirements for CareWell Integrated Care Coordination Pathway (ICCP)?

**How will existing workflows be adapted for CareWell Integrated Care Coordination services?**

**Focus group 1:**

Putting the patient at the centre and establishing cross flows between all parties involved.

**Focus group 2:**

Some flows are already developed or almost finalized (electronic prescription, EHR, web portals,

messaging, etc...). Others, however, especially those related to the coordination of the patient, must be implemented by using conventional systems (involvement, training, dissemination...)

#### **Interviews 1:**

Adapting agendas and promoting non-face-to-face consultations  
 Boosting the scheduled consultation to manage patients proactively.  
 Promoting the comprehensive view of the patient and carers

#### **Interviews 2:**

(answers to the first 3 questions):

Indispensable collaborative work, from design to implementation, where the goal is the provision of high quality healthcare services that can be systematized and reproducible and do not depend solely on certain professionals' motivation.

Define the roles and responsibilities of different professional profiles and describe their activities.

Identify the role of the professional responsible for the patient and that of the consultant professional, and respect both roles.

Provide different means of communication between professionals, which conform to different patient care needs.

### **What changes will healthcare providers have to make to how they work together?**

#### **Focus group 1:**

it is a cultural change.

#### **Focus group 2:**

In our statutory scheme is complicated to give a global response. Anyway, healthcare providers must be partakers of the importance of this need and must be involved

#### **Interviews 1:**

Find common areas to share information and patient management as well as their therapeutic plan and follow-up (inter-level and multidisciplinary)

### **How will responsibility be split between healthcare provider organisation?**

#### **Focus group 1:**

Through the combination of patient needs with the skills of each professional profile and each level of care in relation to the corresponding pathway.

#### **Focus group 2:**

shared responsibility: primary care main responsible for the patient, social care coordinated with healthcare

#### **Interviews 1:**

Promote the role of the nursing as case manager coordinated with GP

Nursing from hospital as a consultant and responsible for acute health problems

Continuity of care is ensured by the coordination of new roles of nursing

### **What are the incentives for sharing information through CareWell Integrated Care Coordination services?**

#### **Focus groups 1:**

better health outcomes, greater efficiency and clinical safety. For professionals, the attainment of the objectives set out in the Contract Clinical Management.

#### **Focus groups 2:**

shared responsibility: primary care main responsible for the patient, social care coordinated with healthcare

#### **Interviews 1:**

The first-hand, quick information based on shared criteria

Solving problems efficiently has an effect on professionals' and patients' satisfaction

The availability of information and training

#### **Interviews 2:**

The motivation of most professionals is the main driver for the use of these tools; confirming its benefits is the best way to maintain it. It is therefore necessary that the operability and usability are suitable.

### **What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?**

#### **Focus group 1:**

Ignorance among professionals of different levels. The culture of "the patient is mine."

#### **Focus group 2:**

Barriers are related to low agility and lack of safety of ICT systems, beyond the professional mistrust between different levels.

#### **Interview 1:**

The distance and lack of direct relationship

Differences in clinical information systems in which information sharing is still parceled and is no longer proportional and not always bidirectional.

The fragmented view of the patient's problems

#### **Interview 2:**

The inherent barriers of the implementation of a new organizational proposal

The inherent barriers in the use of a new technology: adaptation to care objective, economic investment, maintenance and incorporation of improvements ...

### **How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?**

#### **Focus group 1:**

Remaking pathways putting the patient in the central axis and taking into account new technological tools, their efficiency and the sustainability of the system.

Focus group 2: Improving what was said in the previous question.

#### **Interviews 1:**

Unifying criteria and monitoring performance

Clinical guidelines have to be based on evidence and the use of common protocols are necessary

#### **Interviews 2:**

Fundamental changes are procedural in nature, not of processes, so the challenge is the training and the dissemination of these procedures.

### **What time is required for procuring necessary ICT components or systems for CareWell Integrated Care Coordination services?**

#### **Focus group 1:**

Varies depending on the starting point, capacity for allocation of resources and pathway design.

#### **Focus group 2:**

It will depend on the level of development. The implementation of particular ICT depends on the complexity, investment and economic development.

#### **Interviews 1:**

difficult to estimate: the time required to get the technology stable, with proven evidence and with all professionals informed.

#### **Interviews 2:**

It is essential the participation of the professionals involved, so meetings are necessary to agree how to bring ICTs to the procedure. Plan as much as possible the introduction of ICTs, so that the technological tools are consistent and fit.

### **What other organisational changes are envisaged in order to deliver CareWell Integrated Care Coordination services?**

#### **Focus group 1:**

Definition of new roles, coordination with other institutions, provision of new methods of communication: no face-to-face consultations, messaging between professionals, etc..



### Interviews 1:

Change in medical and nursing agendas

New pathways and referral mechanisms

Other reference units: day hospitals, reference internist in acute and subacute hospital ...

## 6.2.2 Puglia pilot site

### Organisational and financial requirements for CareWell Integrated Care Coordination Pathway (ICCP)?

#### How will existing workflows be adapted for CareWell Integrated Care Coordination services?

Creating interfaces among the ICT tools currently in use and the ones introduced by carewell

#### What changes will healthcare providers have to make to how they work together?

Build networks among professionals to facilitate communication and introduce infrastructure to make easier team work

#### How will responsibility be split between healthcare provider organisation?

The professionals responsibility is related to his qualification, job description and activities carried out.

#### What are the incentives for sharing information through CareWell Integrated Care Coordination services?

Incentives can be personals or linked to professional satisfaction, and also organizational by giving new ICT tools to improve performances and motivate the team

#### What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?

Barriers can be considered not enough technology available and sometimes the ones available do not communicate

#### How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?

Inform consent currently in use will be integrated with the one to introduce in Carewell

#### What time is required for procuring necessary ICT components or systems for CareWell Integrated Care Coordination services?

About a year to perform all the necessary administrative procedures

#### What other organisational changes are envisaged in order to deliver CareWell Integrated Care Coordination services?

The current organizational model is not going to change. It will be supported and integrated by introducing the ICT tools and models provided by Carewell

## 6.2.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

## 6.2.4 Veneto pilot site

### Organisational and financial requirements for CareWell Integrated Care Coordination Pathway (ICCP)?

#### How will existing workflows be adapted for CareWell Integrated Care Coordination

### services?

The actual procedure of activation of the multidimensional assessment unit and the home care services procedures have to be adapted in order to be integrated into the patient dashboard. This will allow all the professionals (each one in relation to their parts) to see the global conditions and serviced delivered to a patient.

### What changes will healthcare providers have to make to how they work together?

There are no healthcare providers except from us (the local social and health authority)

### How will responsibility be split between healthcare provider organisation?

There are no healthcare providers except from us (the local social and health authority)

### What are the incentives for sharing information through CareWell Integrated Care Coordination services?

There are no healthcare providers except from us (the local social and health authority).

### What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?

As mentioned before, the main barrier, i.e. the compartmentalization of the services, will be overcome by the Carewell Services and the patient dashboard that will be introduced.

### How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?

There are no healthcare providers except from us (the local social and health authority) that is in charge of all the aspect related to the health of citizens.

### What time is required for procuring necessary ICT components or systems for CareWell Integrated Care Coordination services?

The time required will be absolutely in line with the project schedule in order to ensure the timing of the action planned.

### What other organisational changes are envisaged in order to deliver CareWell Integrated Care Coordination services?

As mentioned before the way patient are "taken in charge" will be modified according to the ICCP pathway.

## 6.2.5 Lower Silesia pilot site

### Organisational and financial requirements for CareWell Integrated Care Coordination Pathway (ICCP)?

#### How will existing workflows be adapted for CareWell Integrated Care Coordination services?

Existing workflows will be facilitated by the fact that some of the issues will be arranged and solved online. Patients could register online, always check their primary personal doctor's schedule, obtain results online and in case of not urgent questions – also ask them online. Care providers should be obliged to answer patients' questions in designated time and if necessary schedule a visit. Health care providers specializing in different fields will need to communicate to integrate data of specific patient to supply him with general and integrative treatment method.

#### What changes will healthcare providers have to make to how they work together?

Establish the way they are due to communicate between themselves and with the patients, e.g. if a

doctor asks his patient to tests himself for specific disease the laboratory results should come online both to the patient and to his primary doctor who will be responsible for commenting the result, answering patient's questions if they ask any, and scheduling a visit if necessary. E.g. doctors responsible for heart problems will be obliged to keep the primary personal doctor up to date with the patient's heart results etc.

#### **How will responsibility be split between healthcare provider organisation?**

Every doctor will be responsible for analysing, commenting their patient's results and communicating with the patient.

In the beginning two people will be designated to make 1 hour group introduction for patients to show them how the online system works. Later every doctor will need to give short introduction to his patient if they ask him for that. Once a month all the care providers will gather to discuss how to improve the platform.

#### **What are the incentives for sharing information through CareWell Integrated Care Coordination services?**

Fast and efficient handling patient's questions concerning various health issues because all the health professionals taking care of a patient will have access and upload patients data to the online system, saving time and money of patient and of hospital personnel, integrative approach to patients health, availability of unbiased information brochures concerning different health issues and advising patient what symptoms are worrying or demand visiting the doctor.

#### **What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?**

The patient needs to travel to the hospital every time he wants to see their new results or consult anything with the doctor, there are long lines in the hospital and doctors don't have enough time to spend with every patient, sometimes patients have no clue how to manage prevention of disease or improve their lifestyle in a way that will help them to keep good health

#### **How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?**

Health care professionals will need to be trained to use the system and establish their new duties

#### **What time is required for procuring necessary ICT components or systems for CareWell Integrated Care Coordination services?**

1 year

#### **What other organisational changes are envisaged in order to deliver CareWell Integrated Care Coordination services?**

Assigning a group of people responsible to solve emerging problems, a person introducing new people to the system and a person responsible for organising focus groups to discuss further improvements or encountered problems regularly.

## 6.2.6 Croatian pilot site

### **Organisational and financial requirements for CareWell Integrated Care Coordination Pathway (ICCP)?**

#### **How will existing workflows be adapted for CareWell Integrated Care Coordination services?**

By implementing new technology and procedures for field nurses and GPs everyday work. In the future, doctors will check patient's medical data provided by field nurse on regular basis. As well, new activities will be performed by field nurses while in the field – new medical measurements (ECG, Spirometer), psychologically support and new educational methods will be introduced. Furthermore, a special procedure will be implemented for the collaboration between social care and field nurses – it will allow for atomized information exchange and data availability.

#### **What changes will healthcare providers have to make to how they work together?**

Informal meetings between field nurses and doctors will be replaced with structured procedure and technology that will enable doctors to access medical data provided by field nurse regardless of time and location – they will be able to see the data in real time or access the history of medical

data for a specific patient when needed.

**How will responsibility be split between healthcare provider organisations?**

The responsibility will stay the same as it is now, it will not change.

**What are the incentives for sharing information through CareWell Integrated Care Coordination services?**

There are no incentives.

**What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?**

At the moment, field nurses keep a separate patient healthcare record that is rarely or never shared with doctor or specialist. By introducing ICT tools, both doctors and specialists will have access to patient's data when needed.

**How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?**

Since there is no consent for the regular healthcare services, it will not be adopted. However, all patients taking part in CareWell services will sign the informed consent.

**What other organisational changes are envisaged in order to deliver CareWell Integrated Care Coordination services?**

None, at the moment.

## 6.3 PATIENT EMPOWERMENT AND HOME-SUPPORT PATHWAY (PEHP) REQUIREMENTS

### 6.3.1 Basque Country pilot site

#### Organisational and financial requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)?

**How will existing workflows be adapted for CareWell Integrated Care Coordination services?**

**Focus group 1:**

move from face-to-face towards non face-to-face activities.

**Focus group 2:**

the pathway will be adapted depending on the ICTs implemented.

**Interviews 1:**

Giving greater emphasis on patient self-monitoring and incorporating the review of this intervention to the professionals' routine

Providing patients and caregivers with resources and education for both self-management and detection of worsening signs

**Interviews 2:**

answers for the first 3 questions

The pathway has to be defined with a clear clinical goal.

Technology has to adapt to the clinical objective

Responsibilities of each actor involved have to be well defined

Actions to be taken in any circumstances should be defined.

Workflows cannot increase the administrative work

The data used must be included in EHR, so it is accessible to all professionals who may patients'

clinical information.

### What changes will healthcare providers have to make to how they work together?

#### Focus group 1:

it is a cultural change, patient-centered care. Healthcare providers have to accustomed to empower patients by using ICT tools.

#### Focus group 2:

agreements, sharing responsibilities... according to the implemented ICTs.

#### Interview 1:

A more consensual way of work and spaces of interaction

Establish mechanisms for mutual understanding and areas of work of each professional.

### How will responsibility be split between healthcare provider organisation?

#### Focus group 1:

Through the combination of patient needs with the skills of each professional profile and each level of care in relation to the corresponding pathway.

#### Focus group 2:

responsibilities will be adapted according to the modifications of the pathway.

#### Interviews 1:

Answers of the previous question

Providing nursing with skills

### What are the incentives for sharing information through CareWell Integrated Care Coordination services?

#### Focus group 1:

better health outcomes, greater efficiency and clinical safety, greater self-managent.

#### Focus group 2:

In our health system incentives are realted to voluntariness and commitment to the institution.

In other systems, however, incentives can be determined depending on the level of involvement.

#### Interviews 1:

Better health outcomes with a shared responsibility with the patient

The satisfaction of both patients and profesioanls.

Avoid or program admissions

#### Interviews 2:

Motivation of the user, so it is necessary to simplify the process and facilitate the implementation avoiding administrative burden.

### What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?

#### Focus groups 1:

Accessibility to services; delay in access to information; lack of training and clinical information to patients about their process.

#### Focus groups 2:

It depends on the level of knowledge of the patient and/or caregiver on home technology to be applied, geographic barriers, etc.

#### Interviews 1:

Time-consuming because of the distance and, and a very very paternalistic patient-professional relationship.

Poor education od patients and uncertain information sent to patients that create confusion

#### Interviews 2:

Involving patients in decision-making and information and training to patients is required

Professionals need time for training the use of ICTs

The use of external platforms implies an extra administrative work and duplication of data storage

### How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?

#### Focus groups 1:

modifying professionals' roles and work practices.

#### Focus group 2:

dissemination, training and implementation.

#### Interviews 1:

Looking free spaces agenda, designing the service portfolio in another way

#### Interviews 2:

procedures and processes have to be agreed and have to respond to care necessities, and data have to be integrated in our own information systems.

### What time is required for procuring necessary ICT components or systems for CareWell Integrated Care Coordination services?

#### Focus group 1:

Varies depending on the starting point, capacity of resource allocation and the target population.

#### Interview 1:

difficult to estimate: the time required to get the technology stable, with proven evidence and with all professionals/patients informed.

#### Interview 2:

telemonitoring tools require high investment, so the deployment time has to be very well planned.

### What other organisational changes are envisaged in order to deliver CareWell Integrated Care Coordination services?

#### Focus group 1:

An adaptation of the activities of the professionals. Training.

#### Interviews 2:

creation of new roles.

#### Interviews 2:

professionals need time to be trained in the use of technology.

## 6.3.2 Puglia pilot site

### Organisational and financial requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)?

#### How will existing workflows be adapted for CareWell Integrated Care Coordination services?

The current data, together with the ones related to the remote monitoring processes will be uploaded on a ICT platform which is in use by the professionals for the ICCM

#### What changes will healthcare providers have to make to how they work together?

The envisaged changes regard the improvement of professionals ability in using telmedicine devices and remote monitoring systems

#### How will responsibility be split between healthcare provider organisation?

The professionals responsibility is related to his qualification, job description and activities carried out.

**What are the incentives for sharing information through CareWell Integrated Care Coordination services?**

Incentives can be personal or linked to professional satisfaction, and also organizational by giving new ICT tools to improve performances and motivate the team

**What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?**

Barriers can be considered not enough technology available and sometimes the ones available do not communicate

**How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?**

Inform consent currently in use will be integrated with the one to introduce in Carewell

**What time is required for procuring necessary ICT components or systems for CareWell Integrated Care Coordination services?**

About a year to perform all the necessary administrative procedures

**What other organisational changes are envisaged in order to deliver CareWell Integrated Care Coordination services?**

Training of patients and care givers about managing their pathological condition and about the use of technology for telemonitoring and teleservice and tele consultation with the professionals responsible for patients.

### 6.3.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 6.3.4 Veneto pilot site

## **Organisational and financial requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)?**

**How will existing workflows be adapted for CareWell Patient Empowerment and Home-support Pathway (PEHP)?**

Actually the empowerment process is in charge of the GP that use education as one of the main tool for self-management of their own patients in relation to each and single needs.

**What changes will healthcare providers have to make to how they work together?**

There are no healthcare providers except from us (the local social and health authority)

**How will responsibility be split between healthcare provider organisation?**

There are no healthcare providers except from us (the local social and health authority)

**What are the incentives for sharing information through CareWell Patient Empowerment and Home-support Pathway (PEHP)?**

There are no healthcare providers except from us (the local social and health authority)

**What are the existing barriers to sharing information that are overcome through CareWell Patient Empowerment and Home-support Pathway (PEHP)?**

As mentioned before, the main barrier, i.e. the compartmentalization of the services, will be overcome by the Carewell Services and the patient dashboard that will be introduced.

**How will established consent procedures currently followed by service providers need to be adapted for CareWell Patient Empowerment and Home-support Pathway (PEHP)?**

**There are no healthcare providers except from us (the local social and health authority) that is in charge of all the aspect related to the health of citizens.**

**What time is required for procuring necessary ICT components or systems for CareWell Patient Empowerment and Home-support Pathway (PEHP)?**

**The time required will be absolutely in line with the project schedule in order to ensure the timing of the action planned.**

**What other organisational changes are envisaged in order to deliver CareWell Patient Empowerment and Home-support Pathway (PEHP)?**

**The scheduling of the access to the patient has to be modified in order to comply with the assisted monitoring plan decided by the GP or the Primary Care Director.**

### 6.3.5 Lower Silesia pilot site

## Organisational and financial requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)?

**How will existing workflows be adapted for CareWell Integrated Care Coordination services?**

Patient's results will be uploaded online to the communication platform and could be analysed by patients from home, registration will be online.

**What changes will healthcare providers have to make to how they work together?**

Communicate through online platform on daily basis, be able to schedule home visit with a patient in case of emergency

**How will responsibility be split between healthcare provider organisation?**

Every doctor will be responsible for analysing, commenting their patient's results and communicating with the patient.

In the beginning two people will be designated to make 1 hour group introduction for patients to show them how the online system works. Later every doctor will need to give short introduction to his patient if they ask him for that. Once a month all the care providers will gather to discuss how to improve the platform.

**What are the incentives for sharing information through CareWell Integrated Care Coordination services?**

Fast and efficient handling patient's questions concerning various health issues because all the health professionals taking care of a patient will have access and upload patients data to the online system, saving time and money of patient and of hospital personnel, integrative approach to patients health, availability of unbiased information brochures concerning different health issues and advising patient what symptoms are worrying or demand visiting the doctor.

**What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?**

The patient needs to travel to the hospital every time he wants to see their new results or consult anything with the doctor, there are long lines in the hospital and doctors don't have enough time to spend with every patient, sometimes patients have no clue how to manage prevention of disease or improve their lifestyle in a way that will help them to keep good health

**How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?**

Health care professionals will need to be trained to use the system and establish their new duties

**What time is required for procuring necessary ICT components or systems for CareWell Integrated Care Coordination services?**

1 year

**What other organisational changes are envisaged in order to deliver CareWell Integrated**

### Care Coordination services?

Assigning a group of people responsible to solve emerging problems, a person introducing new people to the system and a person responsible for organising focus groups to discuss further improvements or encountered problems regularly.

## 6.3.6 Croatian pilot site

### Organisational and financial requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)?

#### How will existing workflows be adapted for CareWell Patient Empowerment and Home-support Pathway services?

Biggest change in workflow is that now field nurses will have a structured procedure for providing educational services and materials to patients and caregivers. On top of structured procedure, they will also use advanced ICT tools for educating patients and providing unified educational materials to all patients. Furthermore, patients will be enabled to access that educational materials after the field nurse has left their home, through ICT technology provided during the CareWell project.

#### What changes will healthcare providers have to make to how they work together?

None changes will be made to cooperation of healthcare professionals for the purpose of PEHP.

#### How will responsibility be split between healthcare provider organisations?

The responsibility will stay the same as it is now, it will not change.

#### What are the incentives for sharing information through CareWell Patient Empowerment and Home-support Pathway services?

The responsibility will stay the same as it is now, it will not change.

#### What are the existing barriers to implementing ICT educational tools through CareWell Patient Empowerment and Home-support Pathway services??

At the moment we do not foresee any specific barriers. As in any other project, when implementing new technology, adequate technical support should be given to all stakeholders that will be using the technology to overcome any resistance to innovation and new technology implementation.

#### How will established consent procedures currently followed by service providers need to be adapted for CareWell Patient Empowerment and Home-support Pathway services??

Since there is no consent for the regular healthcare services, it will not be adopted. However, all patients taking part in CareWell services will sign the informed consent.

#### What other organisational changes are envisaged in order to deliver CareWell Patient Empowerment and Home-support Pathway services??

None, at the moment.

## 7 INITIAL TECHNICAL REQUIREMENTS

Key technical requirements were gathered through interviews and focus groups in order to learn more about the technical needs regarding the development and implementation of CareWell pathways. In contrast to the requirements gathering exercises for healthcare professionals and patients and informal carers the technical requirements interviews and focus groups didn't seek to gather the needs of users of the service but the technical elements which need to be considered for the future service to function well. This exercise of requirements gathering is to prepare the sites not only for the specification of CareWell integration architecture in WP4 and the design of organisational models in WP3 but for the testing and operation of the pilot services in WP5 and WP6.

### 7.1.1 Basque Country pilot site

Type of event: interview or focus group	Interview
Date at which the interview / focus group took place	March 2014
Venue at which the interview / focus group took place	BILBAO
Duration of the interview / focus group	2 HOURS
No. of participants in interview / focus group	1
Type of user groups/stake holders involved	Technical advisor
Recruitment criteria/rationale applied	Expertise on e-health. Project team member.

### 7.1.2 Puglia pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 7.1.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 7.1.4 Veneto pilot site

## Questions to start the focus group interview with key technical experts

### What do you think of the ICT services which are currently provided to patients?

The ICT service which managed patient cure and assistance isn't accessible to patients. It is a system which allow professionals to register their activities like a diary because the processes are oriented to the cure.

### Do you see any advantages or disadvantages of the way services are currently provided?

Yes, there are advantages in the currently service. In fact, at the present time, the coordination of care is activated by a multidimensional assessment unit that prepares an integrated care plan and involves all professionals like GP, the home care service, the ward assistants and, if required, the

social service, and, case by case, a consultant for specific health problem.

As disadvantage the actual ICT system is strictly compartmentalized, i.e. professionals can see only what its service is doing and they don't have a more wide view of the patient.

### **Do you feel the need to improve/change the way services are currently provided (with or the help of ICT)?**

Yes, we feel the need to improve the existing pathways by sharing information on all the medical and home-care services to all the professional involved in the single cases. The patient's dashboard, in the ICT system, will allow this sharing of the information of the patients among all the professionals. The view of this dashboard will be granted to all the clinicians involved in each and single case.

It would be also very important to implement some telemedicine services.

### **Which preconditions need to be met for a successful implementation of ICT applications/services in the healthcare context?**

The first precondition required is to set a good multidisciplinary team. The team has to be composed by all the actors involved in the process of delivery of care services. All the team member should have a proactive mood toward the team work and the technology, that will lead the change within the organization.

The team should be established not only for the development and the first deployment of the ICT services. It should constantly monitor the services also after the mainstreaming, being able to foresee the possible further development or innovation of the system and therefore of the services.

Another precondition it is the sharing of the services delivered and the underlying procedures.

### **If ICT e.g. telecare or telehealth equipment/services are applied what exactly is hampering or facilitating its adequate use?**

Possible obstacles are mainly linked to the transmission of the data. It is essential a 24/7 connection; moreover it required a good risk and contingency plan in case of adverse circumstances such as a block of the trasmissions.

Another obstacle can be a resistance to change, especially in long experienced professionals that are not familiar with the technology.

Among the features that can facilitate the use of the technology: new services should make available constantly updated data available for all the professionals. This will allow an optimization of the time actually consumed in searching and getting informations about every patient and will consent a better coordination and a better pertinence of the care delivered.

si conosce l'esatta posizione dei pazienti in qualsiasi momento.

### **In comparison to services provided without the application of ICT do you see any advantages or disadvantages?**

Yes, we see advantages. In the actual system, the professionals go to the patients with a PDA in which they insert the data about the patients and the services delivered. Once back to the offices they download the data on the Territorial System.

### **Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?**

Thanks to the new ICT System, all the professionals will share the information through the patient's dashboard. They will also be able to request and give consultations and advice through the telecare and teleconsulting in an asynchronous or synchronous way.

These services will improve the coordination of cares to the patients. Moreover these services will allow a better customization of the care delivered to each and single patient. Overall these features will improve the efficiency of the Primary Care District and in a wider perspective the Local Health

Authority's services to the citizens.

Two disadvantages have to be taken into account while introducing new services: the resistance to change and the overall management of the data collected.

### Could you think of any factors hampering or facilitating the implementation of CareWell services?

The structure of the Local Health Authorities as designed by the Veneto Region Social and Health System is a facilitating factor for the implementation of the CareWell services. In fact the integration between social and health care is one of the main features of the Veneto Region Social and Health System. The integration between primary care and secondary care is one of objectives in the Regional Social and Health Care Plan 2012-2016.

One the other hand the integration between the primary and secondary care can be a challenge that will require a special attention.

### Do you see potential of improving the envisaged CareWell services?

The information will be integrated between primary and secondary care, allowing a horizontal vision of the pathway of care of a patient to all the professionals involved. This will also allow an improvement of the healthcare processes, especially when the home care services are involved.

## 7.1.5 Lower Silesia pilot site

Type of event: interview or focus group	meeting
Date at which the interview / focus group took place	4.04 2014
Venue at which the interview / focus group took place	A. Falkiewicz Hospital
Duration of the interview / focus group	2hrs
No. of participants in interview / focus group	7
Type of user groups/stake holders involved	Administration and Clinical users
Recruitment criteria/rationale applied	

## Questions to start the focus group interview with key technical experts

### What do you think of the ICT services which are currently provided to patients?

There are no such services

### Do you see any advantages or disadvantages of the way services are currently provided?

Currently provided services not fully supporting of patients

### Do you feel the need to improve/change the way services are currently provided (with or the help of ICT)?

There is a huge need to support patients with ICT

### Which preconditions need to be met for a successful implementation of ICT applications/services in the healthcare context?

Interoperability is the main precondition to be met for a successful implementation of ICT.

### If ICT e.g. telecare or telehealth equipment/services are applied what exactly is hampering or facilitating its adequate use?

Telecare or telehealth equipment/services are not applied exactly to be hampering or facilitating its adequate use

**In comparison to services provided without the application of ICT do you see any advantages or disadvantages?**

I can see the disadvantages only. Patients have no access to their own information.

**Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?**

Implementation of Care Well platform will support Patients access to integrated health services.

**Could you think of any factors hampering or facilitating the implementation of CareWell services?**

Not yet

**Do you see potential of improving the envisaged CareWell services?**

Yes – Implementation of CareWell services should improve care

### 7.1.6 Croatian pilot site

Type of event: interview or focus group	Interview/technology inspection
Date at which the interview / focus group took place	March 20 <sup>th</sup> , 2014 April 1 <sup>st</sup> , 2014 April 10 <sup>th</sup> , 2014
Venue at which the interview / focus group took place	Zagreb healthcare centres (Tuškanac 23, Bartola Kašića 6, Kruge 44)
Duration of the interview / focus group	1h
No. of participants in interview / focus group	2
Type of user groups/stake holders involved	Doctors
Recruitment criteria/rationale applied	Doctors that will be taking part in CareWell project.

## Questions to start the focus group interview with key technical experts

**What do you think of the ICT services which are currently provided to patients?**

There are no ICT services provided to patient at the moment.

**Do you see any advantages or disadvantages of the way services are currently provided?**

Not applicable, since none are provided at the moment.

**Do you feel the need to improve/change the way services are currently provided (with or the help of ICT)?**

No, since no ICT services are provided at the moment.

**Which preconditions need to be met for a successful implementation of ICT applications/services in the healthcare context?**

Central platform, service design, organizational setup to support service delivery, checks legal barriers, implement logistic support, develop reimbursement model if needed.

**If ICT e.g. telecare or Telehealth equipment/services are applied what exactly is hampering or facilitating its adequate use?**

They are not applied yet towards patients.

**In comparison to services provided without the application of ICT do you see any advantages or disadvantages?**

Most important advantage are speed of information transfer, data collection, interaction possibility, more productivity for healthcare system.

**Regarding the introduction of envisaged CareWell services which advantages or**

### disadvantages do you see?

Above mentioned.

### Could you think of any factors hampering or facilitating the implementation of CareWell services?

Adoption in healthcare system (new service introduction), dedicated time of healthcare professionals, procedure for purchasing new tools.

### Do you see potential of improving the envisaged CareWell services?

Not at the moment.

Technology/functionality related requirements	Service process related requirements	Other requirements
	Organize user trainings to educate patients/caregivers as well as medical teams on how to use ICT technology provided in CareWell project.	
	Ensure adequate technical support for medical teams, patients and caregivers that will be using procured ICT technology for both ICCP and PEHP.	

## 7.2 INTEGRATED CARE COORDINATION PATHWAY (ICCP) REQUIREMENTS

### 7.2.1 Basque Country pilot site

#### Technical requirements for CareWell Integrated Care Coordination Pathway (ICCP)?

##### What are the technical advantages of CareWell ICCP?

Principally the ability to share clinical information among all the members of the care team. Information around the patient is unique and accessible for all the professionals taking care of the patient.

From the technological point of view, we have quite a lot of experience in sharing clinical information within Osakidetza's clinical staff, but not so much experience in sharing information with patients or others actors, i.e. the social workers, that also care for the patients.

##### What technical difficulties do you imagine will be encountered when implementing CareWell ICCP?

The main difficulty will be the total integration of some systems that nowadays are working in "stand alone" mode or which have been recently set up.

Another important question we will face in the implementation phase is the need of displaying training courses and continuous support for professionals with lack of skills in the use of ICT or professionals with new roles in the care pathway.

The implementation of the ICCP will involve new functionalities in our health information system (HIS) and new integration capacities that will have to be shown to the involved professionals.

This project will involve many legal and information security aspects that will have to be dealt with.

The technical architecture is feasible but it will also have to comply with security and confidentiality regulations that will become the framework to do what technically has to be done,

not what can be done.

#### **How will interoperability between legacy systems and CareWell ICCP infrastructure be ensured?**

In the Basque Country, different building blocks of the legacy systems are already in use and interoperating without problems whatsoever. The modules that are to be put in place for the project (videoconsultation, virtual clinical sessions, CRM platform) will be supported by a specific team to attend users' demands and by a team of developers working in three different informatics scenarios, preproduction, production and training. This will allow us to work on the integration step by step without risking the work previously done. Besides, the different teams will be coordinated by tech professionals with a large background and knowledge of Osakidetza's HIS.

#### **Is procurement of technical components required for CareWell ICCP? If so what is the expected scope, cost and time frame?**

Hardware procurement won't be necessary at the moment, but will probably be necessary to subcontract software developers and other specific professionals.

#### **Will new technical components be developed by in house specialists for CareWell ICCP? If so what are the expected costs and time frames?**

New developments for integration and developments for new functionalities of the existing technologies will be necessary. Expected costs and timetables are under study.

### 7.2.2 Puglia pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 7.2.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 7.2.4 Veneto pilot site

## **Technical requirements for CareWell Integrated Care Coordination Pathway (ICCP)**

#### **What are the technical advantages of CareWell integrated care coordination services?**

First of all, the ICCP services will allow a better control of the patients health status. The ICCP services will also improve the functionality of the entire system of care delivery. More data will be available for the professionals in an integrated dashboard of the patient. This will allow the healthcare professionals to have constant updates on the patient and their conditions and whether, for example, the patient is stable at home or he has been admitted to hospital.

#### **What technical difficulties do you imagine will be encountered when implementing CareWell integrated care coordination services?**

As highlighted while answering to other questions, the main technical difficulties will regard on one hand the integration of the territorial ICT system with the Hospital one and the GPs systems; on the other hand the transmission of the data and the integration of the softwares with the medical devices have to be considered with special attention.

#### **How will interoperability between legacy systems and CareWell integrated care coordination services infrastructure be ensured?**

The Territorial ICT system is currently under upgrade therefore it shouldn't present any issue.

#### **Is procurement of technical components required for CareWell integrated care coordination services? If so what is the expected scope, cost and time frame?**

Some devices solutions will be procured for the project: it has been planned to rent some devices that will be used in both the pathways for ensuring the operability of the system.



**Will new technical components be developed by in house specialists for CareWell integrated care coordination services? If so what are the expected costs and time frames?**

The in house specialists will work close with the external service rented in order to ensure the integration of the systems.

## 7.2.5 Lower Silesia pilot site

### Technical requirements for CareWell Integrated Care Coordination Pathway (ICCP)

**What are the technical advantages of CareWell integrated care coordination services?**

integrated care is based on coordination services and should support the remote access.

**What technical difficulties do you imagine will be encountered when implementing CareWell integrated care coordination services?**

Interoperability is the only technological problem.

**How will interoperability between legacy systems and CareWell integrated care coordination services infrastructure be ensured?**

They should use the HL7 standard

**Is procurement of technical components required for CareWell integrated care coordination services? If so what is the expected scope, cost and time frame?**

It is necessary to purchase platform to implement and tablets for testing the CareWell integrated care coordination services. The cost and time frame have to be estimated.

## 7.2.6 Croatian pilot site

### Technical requirements for CareWell Integrated Care Coordination Pathway (ICCP)

**What are the technical advantages of CareWell integrated care coordination services?**

Integration of different health IT systems will enable patient data exchange between medical professionals.

**What technical difficulties do you imagine will be encountered when implementing CareWell integrated care coordination services?**

Non-defined information exchange protocols and lack of guidelines for data propagation through the healthcare system will need to be overcome in order to secure successful integration of various health IT systems.

**How will interoperability between legacy systems and CareWell integrated care coordination services infrastructure be ensured?**

CareWell infrastructure and services will be integrated with existing ICT infrastructure to ensure interoperability.

**Is procurement of technical components required for CareWell integrated care coordination services? If so what is the expected scope, cost and time frame?**

Sure, ICT equipment will have to be procured for patients/caregiver and field nurses. Specifically, smart phones, smart TVs and tablets. As well, android applications will have to be developed to enable the usage of the ICT technology procured.

**Will new technical components be developed by in house specialists for CareWell integrated care coordination services? If so what are the expected costs and time frames?**

Smartphones, tablets and TVs will be provided by third party providers. Platform used will be Ericsson Mobile Health developed by ENT and adopted according to CareWell requirements.

## 7.3 PATIENT EMPOWERMENT AND HOME-SUPPORT PATHWAY (PEHP) REQUIREMENTS

### 7.3.1 Basque Country pilot site

#### Technical requirements for CareWell Patient Empowerment and Home support Pathway (PEHP)?

##### What are the technical advantages of CareWell PEHP?

In Carewell, the technology is just the tool to provide new services and channels of communication to the patient. Actually, the technology is not the advantage; the new service that patient receives through technology is what makes the difference with the current situation. For example, the possibility for the patient to access his/her own clinical information (personal health record), access to relevant information to manage their condition (active treatment, appointments scheduled), the possibility to send clinical information from their home, high accessibility to a health care or social care professional, continuous e-support, coordination of social care and health care professionals.

##### What technical difficulties do you imagine will be encountered when implementing CareWell PEHP?

Probably the main barrier will be the patients' ability to use the technology. The challenge will be to set up an easy to use tech platform in which alternative channels are perfectly integrated: web, telephone, secure mailing, teleconsultations and of course regular face to face contacts with professionals.

Other important technical aspect will be the correct use of telemonitoring devices to both obtain high-quality data and secure data communication under any circumstances.

##### How will interoperability between legacy systems and CareWell PEHP infrastructure be ensured?

As mentioned before different patients' modules are already in use and interoperating without problems whatsoever. The new modules and devices will have to fulfil certain standards and requirements to be fully interoperable.

##### Is procurement of technical components required for CareWell PEHP? If so what is the expected scope, cost and time frame?

Basque Government and under the jurisdiction of Department of Health has Osatek S.A. as a public limited company in charge of managing telecare and telehealth services. These services started in June 2012, when Osatek S.A. issued an invitation to tender for a service contract for the provision of public service of telecare in the Basque Country. The tenderer awarded the contract was the Temporary Business Association GSR-Televida.

In the tender, telecare is defined as the support service and social intervention, which makes use of personal and environmental sensors in the home to enable people to remain safe and independent in their own home for longer. 24-hour monitoring ensures that, should an event occur (social need or emergency situation), the information is acted upon immediately, and the most appropriate response put in train. Apart from telecare services, health telemonitoring is contemplated in one specific section of the framework contract, called socio-health innovation. In this context, it considers the possibility of providing additional and/or complementary services to that of telecare, such as health telemonitoring.

The components required from the framework contract to be provided in PEHP (telemonitoring) are:

- Supply, installation, maintenance and repair of telecare and telehealth equipment placed at user's home.
- User training in using telecare & telehealth devices.
- Call centre (24x7).
- Administrative management of the service.
- Technical management of alarms: filtering and validation of telecare and telehealth alarms.
- Coordination between social and health care resources depending on the protocols defined.
- Immediate care for emergency situations such as fire, thefts or health emergency.
- Periodical follow-up by phone to continuously monitor users' status.
- Regular follow-up visits at home and/or managing agendas and activity reminders.
- Technological infrastructure of the service: provision of devices, phone lines, management software (PNC6 call monitoring and management system from Tunstall), hardware infrastructure (Computer Telephony Integration and a database managed by Sybase).

Concerning the patients' platform, some parts will have to be procured and integration work will be necessary. However, the details of this procurement are not available yet.

**Will new technical components be developed by in house specialists for CareWell PEHP? If so what are the expected costs and time frames?**

Some parts involved in the PEHP are already being built by Osakidetza's technicians and others will be provided as a service-pack at home.

### 7.3.2 Puglia pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 7.3.3 Powys pilot site

These requirements are currently being gathered and will be delivered at a later date.

### 7.3.4 Veneto pilot site

## Technical requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)

**What are the technical advantages of CareWell PEHP?**

The PEHP service will allow to improve the collection and the quality of the data about the patients. This service will also allow to enhance the possibility for patients with chronic and impairing conditions to receive more services directly at home and to avoid transportation to and from the hospitals.

**What technical difficulties do you imagine will be encountered when implementing CareWell PEHP?**

The main difficulties related to this pathways are the procedure of collection of information, the infrastructure of communication (networks) and the respect of the privacy regulations.

**How will interoperability between legacy systems and CareWell PEHP infrastructure be ensured?**

The Territorial ICT system is currently under upgrade therefore it shouldn't present any issue.

**Is procurement of technical components required for CareWell PEHP? If so what is the expected scope, cost and time frame?**

Some devices solutions will be procured for the project: it has been planned to rent some devices that will be used in both the pathways for ensuring the operability of the system.

**Will new technical components be developed by in house specialists for CareWell PEHP? If so what are the expected costs and time frames?**

The in house specialists will work close with the external service rented in order to ensure the integration of the systems.

### 7.3.5 Lower Silesia pilot site

The Lower Silesian pilot site is not yet at a stage where they are able to consider these requirements in full detail. Requirements will be gathered for this pathway at a later date.

### 7.3.6 Croatian pilot site

## Technical requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP)

**What are the technical advantages of CareWell PEHP?**

New delivery channels for educational materials will be developed on TV, smartphone and tablet.

**What technical difficulties do you imagine will be encountered when implementing CareWell PEHP?**

None significant. Technologies that will be used for development of educational ICT tools for field nurses and patients/caregivers are familiar so none significant technical difficulties are expected.

**How will interoperability between legacy systems and CareWell PEHP infrastructure be ensured?**

Educational ICT tools used in PEHP will be integrated with Ericsson Mobile Health system to ensure interoperability. Ericsson Mobile Health system, on the other hand, will be integrated with central healthcare record as the central integration point of all health IT systems.

**Is procurement of technical components required for CareWell PEHP? If so what is the expected scope, cost and time frame?**

Sure, ICT equipment will have to be procured for patients/caregiver and field nurses. Specifically, smart phones, smart TVs and tablets. As well, android applications will have to be developed to enable the usage of the ICT technology procured

**Will new technical components be developed by in house specialists for CareWell PEHP? If so what are the expected costs and time frames?**

Smartphones, tablets and TVs will be provided by third party providers. Platform used will be Ericsson Mobile Health developed by ENT and adopted according to CareWell requirements.



## 8 LEGAL AND REGULATORY REQUIREMENTS FOR CAREWELL

Legal requirements were gathered through interviews with relevant experts to ensure that the proposed CareWell services are legally compliant. Both CareWell pathways were considered during these interviews: Integrated Care Coordination Pathway and Patient Empowerment and Home-support Pathway. The legal requirements template was devised by empirica following desk research on legal situation at European level and approved by Kronikgune.

### 8.1 BASQUE COUNTRY PILOT SITE

<b>Type of event: interview or focus group</b>	<b>Interview</b>
<b>Date at which the interview / focus group took place</b>	March 2014
<b>Venue at which the interview / focus group took place</b>	Bilbao
<b>Duration of the interview / focus group</b>	2hours
<b>No. of participants in interview / focus group</b>	1
<b>Type of user groups/stake holders involved</b>	Technical advisor. Project team member.
<b>Recruitment criteria/rationale applied</b>	Expertise on this matter

### Clinical and device accreditation

**Do existing professional accreditations cover the requirements of the application?**

Yes

**Should the professionals be able to complete all the necessary tasks under their existing accreditations?**

Yes

**How is the professional liability for engagement in the project supposed to be addressed and insured?**

In Osakidetza there is a professional insurance policy for civil liability.

**Is the liability shared between different professional actors? If yes, which and how?**

Actors participating in the project shared liability according with their work and role.

**Is there any element of patient/client liability in the project?**

Yes.

**Do professionals (e.g. clinicians) need to be accredited for delivering services at distance?**

No.

**Will their accreditation be valid at their registration location?**

N/A

**Are the systems or devices used in the application subject to rules of certification (e.g. Medical Device Directive CE certification)?**



YES. Telemonitoring devices

**If yes, are all devices or systems intended for use in the application certified or do substitutions have to be made?**

All of them are certified.

## Professional liability

**Will all the actors of the system envisage liability problems?**

Some of them yes

**Will the accreditation regulation of each actor of the system envisage liability problems?**

No

**Will professional liability be insured?**

Yes. Osakidetza's professionals activity is insured.

**Who will be responsible for what in the system (think about every event)?**

**Will there be any element of patient liability involved?**

Yes. The patient or carer need to fulfil some actions

**Will existing liability insurance mechanisms be sufficient for the application?**

Yes

**Will any new insurance or other mechanisms have to be adopted?**

No

**How will liability between different actors be balanced?**

## Information governance/ legal provisions of setting up EHR

**Are there any legal provisions regarding types and sets of health data of patient's summary?**

Yes, Decree 38/2012 (13th March), about the health record and the rights and obligations of the patients and healthcare professionals with regards to the clinical documentation. This decree establishes a clear definition and update on the contents, use and access of the health record, as well as the rights and obligations of patients and professionals with regards to the clinical documentation registered in all the clinical settings (including big hospitals, primary care centres, Dental Health clinics, podiatrists, clinical psychologists etc.). The aim is to create, for each patient, a unique health record, applying to all (public and private) health care settings within the Basque Country.

**Based on which national/regional legislation EHRs and/or ePrescription services can be set up?**

There are different laws and regulations.

Decree 38/2012 (13th March), about the health record and the rights and obligations of the patients and healthcare professionals with regards to the clinical documentation.

Agreement of Osakidetza's Steering Committee (19th June 2006), that regulates personal files managed by Osakidetza

Instruction 6/2003 of the General Management. Functions and obligations of Osakidetza's staff with respect to the personal data protection. Actuation protocol.

**Based on which legal regime data can be processed among different entities in the health sector?**

Decree 38/2012 (13th March), about the health record and the rights and obligations of the patients and healthcare professionals with regards to the clinical documentation

Basic Law 41/2002 (14th December), which regulates the autonomy of the patient and the rights and obligations with regards to the clinical information and documentation

**Have the EU data protection law already be fully implemented in your country? If not, please explain.**

Yes

**How will the consent for data collection be obtained (written, oral, proxy)?**

Written.

**Will the patient be able to revoke the consent temporarily?**

Yes.

**How will patients clearly be informed about what data are to be collected, who will get access to the data, and for what purposes?**

The health professional in charge of recruiting patients will explain all the aspects of the intervention to the patients. The points to clearly explain are:

- Introduction of the project
- Purpose of the research
- Type of research
- Participant selection
- Voluntary participation
- Procedures and protocol
- Description of process
- Duration
- Risks
- Benefits
- Reimbursements
- Confidentiality
- Sharing results
- Right to refuse or withdrawal
- Contacts
- Certificate of informed consent

**How will patients be given access to the collected data?**

Most of the patients will access through the personal health record.

The patients have the legal right to access their health files and if they are not accessible in electronic format they can ask for access to paper clinical files.

**Will patients be informed if a third party accesses their personal health data?**

Yes.

**Will patients be able to correct or delete data collected about them in the trial?**

Yes.

**Who will have access to data and for what purposes? Will the access to data be determined and limited according to roles of health professionals?**

Though is technically possible for other Osakidetza's professionals to access these data, only professionals involved with the care of the patient should access their data. A log of accesses to patients' records is kept.

### Who will have access to data in case of an emergency

Osakidetza's health care professionals

### How will access to data be controlled (password, ID, ...)

Professional e-card, ID, password.

### How do you guarantee the traceability and legal non-repudiation of access?

Yes

### With whom will data be shared?

Data won't be shared outside Osakidetza. Some specific data will be shown to social care workers within the boundaries of this project.

### Will the data be accessible for secondary use for public health, statistical or research purposes? Is there a legal regime addressing these issues?

Not outside this project.

Yes. Basic Law 41/2002 (14<sup>th</sup> December), which regulates the autonomy of the patient and the rights and obligations with regards to the clinical information and documentation

### Will data be shared among public authorities?

No personalised data will be shared. Public authorities will be informed of the results of the new model of care but there will be no possibility to identify the data subjects.

### Are there legal provisions which either allowing or prohibit the linking of health data with other citizen's data?

Yes. Organic Law 15/1999 (13<sup>th</sup> December) on the Protection of Personal Data

### How will the data be stored, what security measures will be implemented?

Data will be stored in Osakidetza's HIS and more specifically in patients' health electronic record.

### Will there be different types of patient consent? Which approach (opt-in/opt-out) will be applied?

There will be a unique patient consent and the approach will be opt-in. Thus, a sample of patients fulfilling inclusion criteria will be informed of the new model of care but no patient will recruit for the model unless he/she says "yes" to its participation.

### Are there any legal constraints of health data archiving durations? If yes, please specify

Yes. Health data must be securely kept for a certain number of years depending on its part of the patients' health record or part of a clinical trial.

Royal Decree-Law 9947/1999 (11<sup>th</sup> June) which approves the Regulations for Security Measures for files containing personal data.

### What measures will be taken to ensure integrity/non repudiation of transferred/shared data?

### What measures will be taken to ensure accessibility of data by all appropriate parties?

Different user profiles will be available for the different roles under a secured identification process.

## Occupational codes of practice/patient control and responsibility

### Are there any national/regional legally and/or morally binding occupational codes of practice in place besides existing international codes of practice (such as The Declaration of Helsinki, The International Code of Ethics of the International

### Federation of Social Workers, the Good Clinical Practice Directive 2005/28/EC ?

Yes

#### How is the patient's right to be informed guaranteed?

Informed consent

#### How do you guarantee the patient's right to access his/her own data?

Is part of the patients' rights chart in Osakidetza. The rights' chart is publically showed in all centres and website. The patient can access their data through Patients' Attention Services. Specific regulations and laws establish the procedure to access health data and overall any patient can ask support to the Basque Data Protection Agency if they feel their rights are not being taken into account.

See annex for regulations.

#### How do you guarantee the patient's right to rectify his/her own data

Similar procedure as mentioned above

#### How do you guarantee the patient's right to object the processing of his/her own data?

Similar procedure as mentioned above

## 8.1.1 Corresponding legal documents and Local regulations

### a) Basic Legislation on personal data protection, patients' rights and health records.

1. Ley Orgánica 15/1999, de 13 de diciembre, de protección de datos de carácter personal.

<http://www.boe.es/buscar/doc.php?id=BOE-A-1999-23750>

**Organic Law 15/1999 (13<sup>th</sup> December) on the Protection of Personal Data:** this law aims to guarantee and protect personal data, specially to preserve honour and personal and family privacy, as well as to exercise the personal right if case of alteration, loss, misuse or unauthorized access to the data. This is applicable to any personal data in physical or electronic support.

2. Real decreto 994/1999, de 11 de junio, por el que se aprueba el Reglamento de Medidas de Seguridad de los ficheros que contengan datos de carácter personal.

<https://www.boe.es/buscar/doc.php?id=BOE-A-1999-13967>

**Royal Decree-Law 994/1999 (11<sup>th</sup> June), which approves the Regulations for Security Measures for files containing personal data:** the Regulation determines the technical and organizational measures to guarantee the confidentiality and integrity of the information, with the aim of preserving honour, personal and family privacy as well as to exercise the personal right if case of alteration, loss, misuse or unauthorized access to the data. The security measures mentioned are basic measures to be satisfied by all the files containing personal data. This is the Regulation that establishes, for example, the need of creating a security document.

3. Ley/2004, de 25 de febrero, de ficheros de datos de carácter personal de titularidad pública y de creación de la Agencia Vasca de Protección de Datos.

<http://www.euskadi.net/bopv2/datos/2004/03/0401184a.pdf>

**Law/2004 (25th February), about personal data owned by public entities and the creation of the Basque Agency for Data Protection:** it determines different aspects related to the creation, modification and elimination of files, limitations to personal data collection, information to interested parties and security of the files, as well as the procedure for complaints to the Basque Data Protection Agency. It also establishes the creation of the Basque Agency for Data Protection and the Data Protection Register.

4. Ley 41/2002, de 14 de diciembre, Básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica.

[http://www.boe.es/diario\\_boe/txt.php?id=BOE-A-2002-22188](http://www.boe.es/diario_boe/txt.php?id=BOE-A-2002-22188)

**Basic Law 41/2002 (14<sup>th</sup> December), which regulates the autonomy of the patient and the rights and obligations with regards to the clinical information and documentation:**

*the aim* of this law is to regulate the rights and obligations of patients, users and professionals, as well as healthcare settings and services, both public and private, related to the autonomy of the patient and clinical information and documentation.

5. Decreto 38/2012, de 13 de marzo, sobre historia clínica y derechos y obligaciones de pacientes y profesionales de la salud en materia de documentación clínica.  
<https://www.euskadi.net/r48-bopv2/es/bopv2/datos/2012/03/1201512a.shtml>

**Decree 38/2012 (13th March), about the health record and the rights and obligations of the patients and healthcare professionals with regards to the clinical documentation:** this decree establishes a clear definition and update on the contents, use and access of the health record, as well as the rights and obligations of patients and professionals with regards to the clinical documentation registered in all the clinical settings (including big hospitals, primary care centres, Dental Health clinics, podiatrists, clinical psychologists etc.). The aim is to create, for each patient, a unique health record, applying to all (public and private) health care settings within the Basque Country.

**b) Osakidetza's Internal procedures and regulations**

These procedures and regulations determine the specific implementation Osakidetza has done to comply with the laws and decrees explained above.

- c) Acuerdo de 19 de junio de 2006, del Consejo de Administración de Osakidetza, por el que se regulan los ficheros de carácter personal gestionados por Osakidetza.

**Agreement of Osakidetza's Steering Committee (19th June 2006), that regulates personal files managed by Osakidetza.**

- d) Acuerdo de 24 de enero de 2007, del Consejo de Administración de Osakidetza, por el que se modifica la estructura de la Comisión de Seguridad para la protección de datos de Osakidetza..

**Agreement of Osakidetza's Steering Committee (24th January 2007), that modifies the structure of the Security Committee for Personal Data Protection**

- e) Instrucción Nº 2/2003 de la Dirección General de Osakidetza. Modelo organizativo de seguridad para las organizaciones de servicios de Osakidetza.

**Instruction 2/2003 of the General Management of Osakidetza. Security organizational model for the service organizations in Osakidetza**

- f) Acuerdo de 28 de marzo de 2003, del Consejo de Administración de Osakidetza, por el que se crea y se asignan funciones a la Comisión de Seguridad para la protección de datos de Osakidetza

**Agreement of Osakidetza's Steering Committee (28th March 2003), that creates and assigns functions to the Security Committee for the data protection of Osakidetza**

- g) Instrucción Nº 6/2003, De la Dirección General. Funciones y obligaciones del personal de Osakidetza con relación a la protección de datos de carácter personal. Procedimiento de actuación.

**Instruction 6/2003 of the General Management. Functions and obligations of Osakidetza's staff with respect to the personal data protection. Actuation protocol.**

## 8.2 PUGLIA PILOT SITE

These requirements are currently being gathered and will be delivered at a later date.

## 8.3 POWYS PILOT SITE

These requirements are currently being gathered and will be delivered at a later date.



## 8.4 VENETO PILOT SITE

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### Clinical and device accreditation

#### Do existing professional accreditations cover the requirements of the application?

Yes, the existing professional accreditations cover the requirements of the application.

#### Should the professionals be able to complete all the necessary tasks under their existing accreditations?

Yes, the professionals are able to complete all the necessary tasks under their existing accreditations

#### How is the professional liability for engagement in the project supposed to be addressed and insured?

Professional liability in the project will be addressed and ensured in the same way that in the normal clinical practice.

#### Is the liability shared between different professional actors? If yes, which and how?

Yes, liability is shared between different professional actors/clinicians who take care of the patient. Each one is responsible for the data and documents produced by himself

#### Is there any element of patient/client liability in the project?

Yes, patient has the duty to actively participate in the project in the empowerment part.

#### Do professionals (e.g. clinicians) need to be accredited for delivering services at distance?

No

#### Are the systems or devices used in the application subject to rules of certification (e.g. Medical Device Directive CE certification)?

Yes, all devices used in the application has to be CE Certified. In fact, this allowed the placing on the market and putting into service in the territory of the Italian medical devices bearing the CE marking. This marking shows compliance, respectively, to the Legislative Decree no. 46/97 (implementation of Directive 93/42/EEC) for medical devices, to D.Lgs.507/1992 (implementation of Directive 90/385/EEC) for the active implantable devices.

#### If yes, are all devices or systems intended for use in the application certified or do substitutions have to be made?

All devices are marking CE

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### Professional liability

#### Will all the actors of the system envisage liability problems?

No, currently problems related to liability are not envisaged by actors.

#### Will the accreditation regulation of each actor of the system envisage liability problems?

No, currently no problem related to it is envisaged

#### Will professional liability be insured?

Yes, professional liability will be ensured thanks to the insurances already existing in healthcare

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facilities and to the one provided to those who exercise the health professions.

**Will there be any element of patient liability involved?**

No

**Will existing liability insurance mechanisms be sufficient for the application?**

It is believed that the existing insurance mechanism are sufficient for the application

**Will any new insurance or other mechanisms have to be adopted?**

No, the existing insurance mechanisms are sufficient for the application.

**How will liability between different actors be balanced?**

Responsibility is balanced in the project in the same way it is balanced in normal clinical practice. The clinician who takes care of the patient is responsible for the entire duration of his assignment. The person who produces a health document has responsibility on it regardless of the fact that the document or data is inserted into the EHR.

## Information governance/ legal provisions of setting up EHR

**Are there any legal provisions regarding types and sets of health data of patient's summary?**

There are privacy code (Legislative Decree n. 196/2003); Guidelines on the Electronic Health Record and Health File – 16 July 2009 by Italian DPA; Guidelines on electronic Health Record – 11 November 2010 by Italian Board of health and to be published the Decree of President of the Council Ministers; Code of Digital Administration – Legislative decree 235/2010.

**Based on which national/regional legislation EHRs and/or ePrescription services can be set up?**

At national level:

Privacy Code (Legislative Decree n. 196/2003) Guidelines on the Electronic Health Record and Health File – 16 July 2009 by Italian DPA; Guidelines on electronic Health Record – 11 November 2010 by Italian Board of health and - to be published - the Decree of President of the Council Ministers, Code of Digital Administration – Legislative decree 235/2010.

At regional level:

Regional Law 26 June 2012, n. 23

Regional Law 34/2007 "Rules regarding the keeping, preservation and computerization of medical records and the informed consent forms"

**Based on which legal regime data can be processed among different entities in the health sector?**

Mainly Privacy Code (Legislative Decree n. 196/2003) and Digital Administration Code (Legislative Decree 238/2010 in force since January 25, 2011)

**Have the EU data protection law already be fully implemented in your country? If not, please explain.**

Yes, Legislative Decree n. 196/2003 has implemented Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

**How will the consent for data collection be obtained (written, oral, proxy)?**

Legislation does not require that consent has a written form. Consent will be registered online and only in residual cases can have a written form.

**Will the patient be able to revoke the consent temporarily?**

Yes, law establishes that patient can revoke his consent at any time.

**How will patients clearly be informed about what data are to be collected, who will get access to the data, and for what purposes?**



An information sheet is produced to inform patient about what data are to be collected, who will have access to the data, and for what purposes

#### **How will patients be given access to the collected data?**

The patients will be provided with user name and password.

#### **Will patients be informed if a third party accesses their personal health data?**

The data can be seen by the patient and by the healthcare professional that produced them. They are also visible to those who take care of the patient in accordance with established policies visibility and shared by the patient.

#### **Who will have access to data and for what purposes? Will the access to data be determined and limited according to roles of health professionals?**

The patients decide who can see his/her medical data. The subjects who can access to data are indicated by the patient according to predetermined policies and upon the patient consents for diagnosis, treatment and rehabilitation.

Yes, the access to data will be determined according to roles of health professionals.

#### **Who will have access to data in case of an emergency**

In case of emergency, the doctor who takes care of the patient in a state of emergency can have access to his/her data, if these are made visible by the patient. It is necessary that clinician declares that access to data is done due to emergency situation.

#### **How will access to data be controlled (password, ID, ...)**

Thanks to the use of credentials the accesses are controlled and are traced in log.

#### **How do you guarantee the traceability and legal non-repudiation of access?**

Traceability is guaranteed by the creation of audit messages. This messages trace relevant events related to Personal Health Information's creation/disclosure/accesion. These log messages are stored in a secure way and can be accessed by Security Officer for monitoring purposes and back-office analysis. About non-repudiation of accesses, each system involved in the data-sharing infrastructure shall implement a system authentication using a digital certificate associated to the system itself. The entity is identified by a trusted Identity Provider that provides a digital signed ticket (identity assertion) to the clinical data collector.

#### **With whom will data be shared?**

All healthcare professionals that take part of the care pathway of the patient in the patient has expressed consent.

#### **Will the data be accessible for secondary use for public health, statistical or research purposes? Is there a legal regime addressing these issues?**

Yes, data can be accessible for secondary use, and a legal regime is being drafted. We can in any case refer to the above-mentioned legal framework.

#### **Will data be shared among public authorities?**

Yes

#### **Are there legal provisions which either allowing or prohibit the linking of health data with other citizen's data?**

Legislation that allows the processing of data and establishes the rules by which this treatment can be done is mainly Privacy Code (Legislative Decree n. 196/2003) and Digital Administration Code (Legislative Decree 238/2010 in force since January 25, 2011)

#### **How will the data be stored, what security measures will be implemented?**

Data characterized by high confidentiality are stored in a encrypted way. Only entities identified by a trusted Identity Provider, and previously authorized by a Authorization/Policy Manager obtain access to requested data.

#### **Will there be different types of patient consent? Which approach (opt-in/opt-out) will be applied?**

Yes, there are different types of consent. The main ones are the consent to enter medical records into the EHR and the consent to which clinicians can see medical records integrate into the EHR

#### **Are there any legal constraints of health data archiving durations? If yes, please specify**



There is no specific law establishing how to manage the maintenance of clinical documents in the course of time. The clinical documents must be maintained in the course of time by the organization that produced them

The internal medical record (hospitalization) with all the included documents must be maintained endlessly

What is not included in medical record has different conservation times, depending on the type of document

#### **What measures will be taken to ensure integrity/non repudiation of transferred/shared data?**

The retrieval of data is performed through encrypted communications. Data are collected within clinical documents signed by the creator. The Consumer of this data should verify their integrity validating the signature of the document itself.

#### **What measures will be taken to ensure accessibility of data by all appropriate parties?**

The doctor asking access to EHR is authenticated by the LHA facility where he/she works. In accordance with his/her role, the doctor will have access for a specified period of time to certain documents, in accordance with established policies visibility and shared by patient.

Patient can access to his/her HER eat every time he/he wants.

## **Occupational codes of practice/patient control and responsibility**

#### **Are there any national/regional legally and/or morally binding occupational codes of practice in place besides existing international codes of practice (such as The Declaration of Helsinki, The International Code of Ethics of the International Federation of Social Workers, the Good Clinical Practice Directive 2005/28/EC)?**

Code of medical ethics and other legislation with regards to local ethics committee.

#### **How is the patient's right to be informed guaranteed?**

Thanks to the information sheet, the patient is informed about what data are to be collected, who will get access to the data and for what purposes.

#### **How do you guarantee the patient's right to access his/her own data?**

Through the use of login credentials, the patient can do it whenever he/she wants.

#### **How do you guarantee the patient's right to rectify his/her own data**

Clinical record produced by the LHA inserted in EHR can not be rectified by the patient. Patient can modify data inserted by himself accessing in his/her PHF.

#### **How do you guarantee the patient's right to object the processing of his/her own data?**

Patient can object the processing of his her own data at any time. In the information sheet are clarify manners to exercise his rights.

## **8.5 LOWER SILESIA PILOT**

<b>Type of event: interview or focus group</b>	<b>meeting</b>
<b>Date at which the interview / focus group took place</b>	4.04.2014 and 24.04.2014
<b>Venue at which the interview / focus group took place</b>	Falkiewicz Hospital
<b>Duration of the interview / focus group</b>	2hrs
<b>No. of participants in interview / focus group</b>	7



<b>Type of user groups/stake holders involved</b>	Administration and Clinical users
<b>Recruitment criteria/rationale applied</b>	meeting

## Clinical and device accreditation

### Do existing professional accreditations cover the requirements of the application?

Not yet

### Should the professionals be able to complete all the necessary tasks under their existing accreditations?

Professionals will need to undergo additional trainings to obtain accreditations

### How is the professional liability for engagement in the project supposed to be addressed and insured?

Special agreements need to be created; patients should have possibility to give feedback about the program

### Is the liability shared between different professional actors? If yes, which and how?

It is going to be shared. Functioning of the system will be a responsibility of informaticians engaged in it and content of the program will be a responsibility of doctors. Patients will have to know the content introduced by doctors.

### Is there any element of patient/client liability in the project?

Yes, patients will be obliged to read information delivered to them by doctors.

### Do professionals (e.g. clinicians) need to be accredited for delivering services at distance?

yes

### Will their accreditation be valid at their registration location?

yes

### Are the systems or devices used in the application subject to rules of certification (e.g. Medical Device Directive CE certification)?

Yes

### If yes, are all devices or systems intended for use in the application certified or do substitutions have to be made?

They are certified. More equipment need to be bought

## Professional liability

### Will all the actors of the system envisage liability problems?

yes

### Will the accreditation regulation of each actor of the system envisage liability problems?

yes

### Will professional liability be insured?

yes

### Who will be responsible for what in the system (think about every event)?

Informaticians for the system functioning, lawyers for accreditations and updates in laws, doctors for system content, patients for receiving the information, responsible person for organizing meetings about the program, one person for educating new users about the system

### Will there be any element of patient liability involved?



Yes, patients will be obliged to read information delivered to them by doctors.

**Will existing liability insurance mechanisms be sufficient for the application?**

no

**Will any new insurance or other mechanisms have to be adopted?**

yes

**How will liability between different actors be balanced?**

Informaticians for the system functioning, lawyers for accreditations and updates in laws, doctors for system content, patients for receiving the information, responsible person for organizing meetings about the program, one person for educating new users about the system

## Information governance/ legal provisions of setting up EHR

**Are there any legal provisions regarding types and sets of health data of patient's summary?**

yes

**Based on which national/regional legislation EHRs and/or ePrescription services can be set up?**

Polish and EU

**Based on which legal regime data can be processed among different entities in the health sector?**

Act on electronic medical information from December 2012

**Have the EU data protection law already be fully implemented in your country? If not, please explain.**

yes

**How will the consent for data collection be obtained (written, oral, proxy)?**

WRITTEN

**Will the patient be able to revoke the consent temporarily?**

Yes

**How will patients clearly be informed about what data are to be collected, who will get access to the data, and for what purposes?**

During an introduction session to the system

**How will patients be given access to the collected data?**

Through the internet

**Will patients be informed if a third party accesses their personal health data?**

Yes

**Will patients be able to correct or delete data collected about them in the trial?**

No

**Who will have access to data and for what purposes? Will the access to data be determined and limited according to roles of health professionals?**

Doctors and patients (Under patient's allowance also their caretakers) to communicate and analyse data. The access will be limited according to the roles of health professionals.

**Who will have access to data in case of an emergency**

Doctor, patient, patient's family and caretaker

**How will access to data be controlled (password, ID, ...)**

Passwords, ID, security system

**How do you guarantee the traceability and legal non-repudiation of access?**

Security systems delivered by professional informatics companies

**With whom will data be shared?**

Doctor, patient, patient's family and caretaker (if allowed by patient)

**Will the data be accessible for secondary use for public health, statistical or research purposes? Is there a legal regime addressing these issues?**

No, personal data will not be available, statistical data can be used for research purposes and a special regulation will be created for it

**Will data be shared among public authorities?**

no

**Are there legal provisions which either allowing or prohibit the linking of health data with other citizen's data?**

yes

**How will the data be stored, what security measures will be implemented?**

Will there be different types of patient consent? Which approach (opt-in/opt-out) will be applied?

**Are there any legal constraints of health data archiving durations? If yes, please specify**

Yes, data has to be stored in the hospital for 20 years

**What measures will be taken to ensure integrity/non repudiation of transferred/shared data?**

Security system needs to be created, number of entries can be one of the measures

**What measures will be taken to ensure accessibility of data by all appropriate parties?**

Agreement will be made between hospital and patient, there will be a lawyer to whom patient can address his problems and a person to whom its possible to give feedback about the system

## Occupational codes of practice/patient control and responsibility

**Are there any national/regional legally and/or morally binding occupational codes of practice in place besides existing international codes of practice (such as The Declaration of Helsinki, The International Code of Ethics of the International Federation of Social Workers, the Good Clinical Practice Directive 2005/28/EC) ?**

yes

**How is the patient's right to be informed guaranteed?**

In legal agreements between patient and hospital

**How do you guarantee the patient's right to access his/her own data?**

In the same agreement

**How do you guarantee the patient's right to rectify his/her own data**

There is no such possibility

**How do you guarantee the patient's right to object the processing of his/her own data?**

Patient will need to give his written decision about it

## 8.6 CROATIAN PILOT SITE

<b>Type of event: interview or focus group</b>	<b>Interviews</b>
<b>Date at which the interview / focus group took place</b>	March/April
<b>Venue at which the interview / focus group took place</b>	Health Centre Zagreb
<b>Duration of the interview / focus group</b>	45 min



<b>No. of participants in interview / focus group</b>	2
<b>Type of user groups/stake holders involved</b>	Head, nurses
<b>Recruitment criteria/rationale applied</b>	SMEs

## Clinical and device accreditation

### Do existing professional accreditations cover the requirements of the application?

Yes, since field nurses and GPs have been educated and trained to perform such and similar activities.

### Should the professionals be able to complete all the necessary tasks under their existing accreditations?

Yes they should.

### How is the professional liability for engagement in the project supposed to be addressed and insured?

It is addressed via head of the Health care polyclinic, and via their working agreements and working licences.

### Is the liability shared between different professional actors? If yes, which and how?

Each professional actor (medical care provider) is responsible for patients, and the shared part is in management team of the polyclinic.

### Is there any element of patient/client liability in the project?

No, but anyway patient informed consent will be signed by each patient.

### Do professionals (e.g. clinicians) need to be accredited for delivering services at distance?

No, they will not need to get accreditation. However, to ensure that medical teams can use the equipment the training and education will be organized. Support services will be available to all participants during the project preparation and pilot site execution activities.

### Will their accreditation be valid at their registration location?

Yes they will.

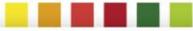
### Are the systems or devices used in the application subject to rules of certification (e.g. Medical Device Directive CE certification)?

SW system Ericsson Mobile Health (EMH) is according to its intended use classified as Class I medical device, while the sensor devices are classified as medical devices of Class IIa and IIb.

### If yes, are all devices or systems intended for use in the application certified or do substitutions have to be made?

SW system used in the pilot will be based on certified product called Ericsson Mobile Health (EMH). EMH is certified as Class I medical device according to MDD. Several adjustments will be added to EMH in order to accommodate requirements from CareWell, but without changing the intended purpose of the product. These adjustments will not be certified as they will be used in pilot site only, but the ethic committee of the polyclinic will need to review the adaptations and give their consent for usage.

Sensor devices (Blood pressure monitor, Glucometer, etc.) used for taking measurements are approved for connection with EMH and have their own CE marking as medical devices according to MDD.



## Professional liability

### Will all the actors of the system envisage liability problems?

No problems can be seen at this point.

### Will the accreditation regulation of each actor of the system envisage liability problems?

No problems can be seen at this point.

### Will professional liability be insured?

Professional liability is already insured in several laws that regulate health care.

### Who will be responsible for what in the system (think about every event)?

Responsibilities are predefined

### Will there be any element of patient liability involved?

No, patients will not be liable since they will sign the informed consent.

### Will existing liability insurance mechanisms be sufficient for the application?

Yes they will.

### Will any new insurance or other mechanisms have to be adopted?

No new mechanisms need to be adopted.

### How will liability between different actors be balanced?

Through ethical approval of the project and through defined work procedure for all stakeholders that are involved in pilot execution.

## Information governance/ legal provisions of setting up EHR

### Are there any legal provisions regarding types and sets of health data of patient's summary?

Health data that are collected from patient and stored in the healthcare system are defined in several specifications defined by the Ministry of Health. Operator of the primary healthcare ICT system is the national insurance company (HZZO) that is appointed by the Ministry of Health as a provider of ICT systems that are used in healthcare.

Carewell data will be collected and stored in separate system, while the integration to EHR will need to be in line with the specifications issued by Ministry of Health.

### Based on which national/regional legislation EHRs and/or ePrescription services can be set up?

Specifications defined by the Ministry of Health that are in line with the provisions of laws in healthcare.

### Based on which legal regime data can be processed among different entities in the health sector?

Several laws on health care.

### Have the EU data protection law already be fully implemented in your country? If not, please explain.

Yes, the Act on Personal Data Protection (Croatian law) has been harmonized in all important questions with the Directive 95/46/EC on the Protection of individuals with regard to the processing of personal data and on the free movement of such data.

### How will the consent for data collection be obtained (written, oral, proxy)?

Consent will be given in writing, first the approval of the ethical committee will be

acquired and then patient informed consent.

**Will the patient be able to revoke the consent temporarily?**

Yes they will.

**How will patients clearly be informed about what data are to be collected, who will get access to the data, and for what purposes?**

They will be informed in written consent document and fully informed by their GP and field nurse.

**How will patients be given access to the collected data?**

Through web portal and GP team.

**Will patients be informed if a third party accesses their personal health data?**

Yes. In case there are changes in which people access the data other than the GP and field nurses involved in the project.

**Will patients be able to correct or delete data collected about them in the trial?**

Not for now, the deletion of medical data is not enabled in the solution, but the note can be added to incorrect data if patient wishes so.

**Who will have access to data and for what purposes? Will the access to data be determined and limited according to roles of health professionals?**

GPs, field nurses and patient caregivers will be allowed to see patient data. For those patients where there is the need to include social worker, some of the patient data will also be available. Access for particular role will be determined and limited according to defined rules.

**Who will have access to data in case of an emergency**

Same stakeholders as listed above.

**How will access to data be controlled (password, ID, ...)**

All users of the system need to be defined in the system (provisioned) to use it and to access the system they need to have their username and password.

**How do you guarantee the traceability and legal non-repudiation of access?**

For all data entered in the system it can be seen who and when entered the data. Also, it can be seen with which equipment the measurements have been done.

**With whom will data be shared?**

GP team (doctor, field nurse), patient and caregiver, and if necessary social worker.

**Will the data be accessible for secondary use for public health, statistical or research purposes? Is there a legal regime addressing these issues?**

If the data need to be accessed for secondary use this will be regulated through ethical approval of the project.

**Will data be shared among public authorities?**

Not for now.

**Are there legal provisions which either allowing or prohibit the linking of health data with other citizen's data?**

Yes.

**How will the data be stored, what security measures will be implemented?**

Data will be stored at secured location; only authorized personnel can access the data.

**Will there be different types of patient consent? Which approach (opt-in/opt-out) will be applied?**

There will be an opt-in patient consent for the involvement in the project, and there will be option for the patient to revoke that consent and exit the project.

**Are there any legal constraints of health data archiving durations? If yes, please specify**

No.

**What measures will be taken to ensure integrity/non repudiation of**

**transferred/shared data?**

For now we do not see that the data will be shared.

**What measures will be taken to ensure accessibility of data by all appropriate parties?**

Pilot setup will include education of all involved parties and there will be support provided during entire pilot.

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## **Occupational codes of practice/patient control and responsibility**

**Are there any national/regional legally and/or morally binding occupational codes of practice in place besides existing international codes of practice (such as The Declaration of Helsinki, The International Code of Ethics of the International Federation of Social Workers, the) ?**

Yes, there are several laws in place; specific laws exist for doctors, for nurses, etc. Also there are laws in place that protect patient data privacy.

**How is the patient's right to be informed guaranteed?**

Through Protection of patient data law.

**How do you guarantee the patient's right to access his/her own data?**

Patient/caregiver will have access to their data through web application.

**How do you guarantee the patient's right to rectify his/her own data**

Personal data can be rectified by authorized users of the system, while collected medical data (measurements) can be rectify by authorized user by adding a note to specify that they are not to be used.

**How do you guarantee the patient's right to object the processing of his/her own data?**

Patient will sign the consent that will involve handling of patient data.

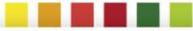
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## 9 NEXT STEPS

The requirements captured by the pilot sites and included in this deliverable need to be consolidated into key service design conditions to form the corner stones of further service development. These consolidated requirements will then inform the development of use cases, organisational models and integration architecture. Specifically, the impact of the key requirements on use case design will be reported in the upcoming design work packages' deliverables:

- D2.2 Use cases for CareWell integrated care models and pathways
- D3.1 CareWell organisational & service process models
- D4.1 Pilot level Service Specification for CareWell services

Following the design work packages, the requirements will also be included and reflected upon in the work in work package 5 in the testing and implementation of the pilot services based on the final versions of the use cases delivered in D2.2.



## 10 ANNEX

In this chapter are the standard requirements gathering templates. Both the patient and informal carers and the healthcare professional requirements templates contained a technical annex with guidance on how to conduct focus groups and interviews and gather requirements. To avoid repetition only the technical annex of the patient and informal carer requirement template is included here, as it is the same for the healthcare professional requirements template.

### 10.1 PATIENT AND INFORMAL CARER REQUIREMENT TEMPLATE

Key patient and informal carer requirements should be gathered through interviews and / or focus groups.

These focus group interviews with patients and informal carers will help the project to learn more about the group specific needs regarding the development and implementation of CareWell pathways. Since the interviews are structured and directed focus group interviews are an effective way of gathering a lot of in-depth and nuanced information in a relatively short time.

Attached to this questionnaire template you will find a technical annex consisting of (I) a short methodological guidance, serving as an introduction to focus group interviews and (II) an exemplary consent form. In order to ensure good conduct we recommend to read through it carefully before you start the interview. For some more information on focus group interviews please refer to the following website, offering a good but more general overview:

<http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conduct-focus-groups/main>

Beginning with introductory, ice-breaking questions we've already developed some PEHP specific questions , however please also add your own.

Please specify:

Type of event: interview or focus group	
Date at which the interview / focus group took place	
Venue at which the interview / focus group took place	
Duration of the interview / focus group	
No. of participants in interview / focus group	
Type of user groups/stake holders involved	
Recruitment criteria/rationale applied	



## Introductory Questions

### Questions to start the focus group interview with patients and informal carer

**Do you use ICT equipment like computer, smart phones, tablet PCs for private purposes?**

**How do you stay in contact with your family and friends? Do you write e-mails and/or make use of social networks like facebook or Twitter? Have tried using services like skype or other video conferencing software?**

**In general what advantages or disadvantages do you see in using ICT applications?**

**How do you evaluate the healthcare services you are currently receiving (with or without help of ICT)?**

**Do you see any advantages or disadvantages of the way services are currently provided?**

**Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?**

**Could you think of any ICT application or service which might help improving your health status?**

**Do you currently make use of healthcare specific ICT e.g. telecare or telehealth equipment/services?**

**Can you imagine that CareWell services will address any of your personal need e.g. healthcare related needs?**

**Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you envisage?**

**Could you think of any factors hampering or facilitating the implementation of CareWell services?**

**Are you willing to use new ICT in general and/or CareWell services in particular?**

**(Please add further questions here)**

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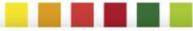
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## TECHNICAL ANNEX



# METHODOLOGICAL GUIDANCE ON FOCUS GROUP INTERVIEWS

## Methodological guidance on how to involve envisaged users of the CareWell technical system in requirements elicitation

### Aims and expected outcomes

According to the project's work plan, user involvement in service requirements elicitation and use case development is planned to be achieved by means of focus groups and interview sessions. These have two aims:

1. To systematically collate information on the experiences and opinions of the envisaged users of the CareWell technical systems (e.g. medical care staff, informal/voluntary carers and older end users) in relation to relevant services as they are currently provided. This would in turn shape the general assessment of expectations, needs, most common situations and problems that the users face, creating the basis for the development of a realistic use cases for the new CareWell services.
2. As far as this is possible at this stage, to collate user requirements that are specifically related to the envisaged CareWell services and the needs, preferences and expectations users have in relation to them.

### General approach

To adequately cater for the particular circumstances prevailing in each pilot site the research methods and techniques set out in the Technical Annex are intended to be applied in a flexible manner. In this sense, the remainder of this document provides generic guidance on how the individual work steps may best be conducted at pilot region level.

### Preparation

#### User groups to be involved

Different service scenarios are envisaged to be piloted within CareWell, and the user groups that need to be involved in requirements elicitation may vary accordingly. Key user groups that are of relevance to the particular service in question need to be identified at each region. This means establishing access to the groups in question, identifying people who are willing to become engaged and conducting the research together with them. It may also be worth considering whether the same people may be asked to work with the project again at a later stage (e.g. in prototype testing) in order to minimize recruitment effort and to allow people to "grow with the project".

It can be expected that in each region, relevant user groups will include both professional and non-professional users. Note that in this context the term "user" is applied in a wide sense and encompasses all people that will come in touch with system and service. Within these two high-level categories, different user groupings may be envisaged as follows:

- patients: older / fragile people with complex needs in need of medical support
- family and other informal carers
- health care professionals
- people engaged in voluntary care provision
- service centre staff involved in triage/response processes

An appropriate recruitment strategy needs to be developed at pilot region level. Recruitment of patient end users may for instance rely upon sampling from client databases typically maintained by service provider organisations.

In relation to older people and informal carers you should apply the same inclusion and exclusion criteria as you envisage for the actual service / pilot, as far as you have defined those already.

In relation to organisations, the general selection criterion is that they play an active role either in service provision or in service financing, i.e. can contribute to the analysis of either staff / organisational or business requirements. Within each relevant organisation it will usually be sufficient to involve representatives of those staff groups that are most actively involved in the service.

The selection of appropriate participants for the requirements analysis can be challenging, particularly when you are still at an early stage of service definition. If you feel unsure or have any questions or concerns, you can contact the colleagues at empirica for support.

### **Guiding research questions**

Preparatory work should also include the formulation of a set of research questions to guide focus group discussions and interviews. Again, the research questions need to take into account the characteristics of the particular service in the region and of the user groups to be addressed. To help you in the formulation of your research questions, we have outlined several general questions for different user groups which are included in the templates.

### **Logistics**

#### **When it comes to logistics, there are several aspects that deserve attention:**

- Overall, how many focus group sessions need to be organised? How many users are expected to participate in each session? Usually, having more than 8-10 people in a focus group will seriously hamper effectiveness. Up to that size, users of one "type" (i.e. patients, informal carers, professionals) can be invited into one focus group event.
- Which types of users are to be involved at each session? How would a suitable recruitment process best be organised? The first aspect depends on your selection criteria, while the second depends on the organizations, user groups etc that exist at your site and that you have access to.
- What information should invitees receive in advance? Is it necessary to generate any information materials in advance? Usually both professional and non-professional users will appreciate at least a short written information beforehand (1-2 pages), describing the background, what you want to do in concrete terms and what you expect in terms of results.
- What research materials need to be prepared in advance (e.g. list of research questions to guide group discussions, paper-based questionnaire to be completed by the participants of other individuals)? As described above, you should formulate concrete research questions based on the general dimensions provided and any other aspect that you deem relevant. For some aspects it may make sense to include a paper/pencil questionnaire to be filled-in by participants, e.g. at the end of the session.
- At which venue should each session take place? Is the venue accessible to all participants, e.g. people using a walker or a wheel chair? The venue should be easy to reach, reasonably well equipped for the purpose and allow the conduction of an undisturbed session. Cold and hot drinks and some cookies will usually be appreciated.
- How long should each focus group session last? Might the anticipated length of the session put an undue burden on (some) participants, e.g. people with reduced physical/mental capacities? Put yourself in the position of your participants. A session of more than two hours of intense discussion and idea-generation will put a strain even on a well-trained professional. Ideally foresee a short break after one hour.

### **Conduction**

It has proved useful in comparable research contexts to compose focus group sessions of a group discussion on the topics set out in your list of research questions together with an individual questionnaire. It has further proved useful that focus groups are organised and led by a suitable and experienced professional, together with an independent observer who should be capable of assessing implications of the interventions made by the participants in relation to service-related requirements and feasibility related aspects. Video/audio recording of the focus group session may be useful as well. If this is deemed inappropriate the session should at least be documented in writing.

#### **In procedural regard, it may be worth paying attention to a number of aspects:**



- Enable a round of introduction involving all participants. Make sure that the roles of the participating project team members are known to the participants (e.g. moderator, rapporteur, technical expert).
- Obtain consent about participation/recording (in written form, an exemplary consent form in English language is annexed to this document). Any additional requirements on obtaining consent from the participants that may be imposed by national regulation/legislation should be covered by the consent form you use.
- Briefly introduce the CareWell project to the participants (e.g. aims, funding context, participants, expected outcomes and envisaged utilization beyond the project duration). Make sure that all participants share a good understanding what the project is about.
- Explain the focus group session's rationale and the way the participants' contributions will be further utilized within the overall project. Make sure that participants understand why they were asked to participate and what you expect to learn from their contribution.
- Encourage participants to make an intervention and ask questions at any time. Try to create an open discussion atmosphere.
- When asking participants to complete a questionnaire, make sure that people who have difficulties in reading or filling in the questionnaire get personal assistance.

### **Reporting**

The involvement of different types of users at this early stage of the project is intended to guide the further process of use case development and service specification internal to the project. Outcomes should therefore be reported in a clearly structured and concise manner, whereby reporting should aim at covering all aspects that may be of relevance in relation to further use case development and service specification. At least three structural elements should be addressed as follows.

Experience shows that one person present during the focus group should deal specifically with note-taking and reporting. Audio or video recordings may be helpful, but will require the consent of the participants.

### **Summary profile of the event**

A summary profile should be provided for each focus group session in terms of:

- Date at which the event took place
- Venue at which the event took place
- Duration of the event
- No. of participants
- Type of user groups involved
- Recruitment criteria/rationale applied

### **Brief summary of the main themes discussed**

The main themes that were discussed should be summarised. These may be presented in a bullet point format. As far as appropriate, key arguments/stand points put forward by the participants should be summarised in a generic manner as well.

### **Synthesised list of requirements on the envisaged service**

A list of requirements on the envisaged service should be derived from the group discussions/questionnaire. They should be structured according to three sub-headings headings as follows::

- Service process related requirements
- Technology/functionality related requirements
- Other requirements

### **Other issues that came up**

Briefly describe all other issues, interventions or comments that came up and seem noteworthy, but are not part of the requirements list.



**Exemplary consent form**

**CareWell Focus Group Consent Form**

I have spoken to.....about the focus group organised in the framework of the CareWell project.

This took place on .....

(Tick one)	YES	NO
I have been informed about the project.	( )	( )
I have had the chance to talk about the project and ask questions.	( )	( )
I know enough about the project now.	( )	( )
I understand that it is my decision whether or not to take part in the focus group session.	( )	( )
I understand that if I do not want to take part, or decide to stop, this will not affect any help I am getting.	( )	( )
I understand that the focus group session may be taped. I can stop this at any time.	( )	( )
I agree to take part in the focus group session.	( )	( )
Optional: I agree to the session being recorded.	( )	( )

\_\_\_\_\_  
Signed                  Date

\_\_\_\_\_  
Name (in block letters)

\_\_\_\_\_  
Signed (Researcher)                  Date

\_\_\_\_\_  
Name(in block letters)



## 10.2 HEALTHCARE PROFESSIONAL REQUIREMENTS TEMPLATES

Key healthcare professional requirements, both for primary and secondary / tertiary care, should be gathered through interviews and / or focus groups. These focus groups interviews with healthcare professionals will help the project to learn more about the group specific needs regarding the development and implementation of CareWell pathways; therefore please hold **two separate focus groups**, one for primary care professionals and one for secondary / tertiary care professionals.

Attached to this questionnaire template you will find a technical annex<sup>1</sup> consisting of (I) a short methodological guidance, serving as an introduction to focus group interviews and (II) an exemplary consent form. In order to ensure that focus group interviews are conducted well we recommend reading through it carefully before you start the interview. For more information on focus group interviews please refer to the following website, offering a good but more general overview:

<http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conduct-focus-groups/main>

Beginning with introductory, ice-breaking question we've already developed some ICCP and PEHP specific questions , however please add your own.

Please specify:

Type of event: interview or focus group	
Date at which the interview / focus group took place	
Venue at which the interview / focus group took place	
Duration of the interview / focus group	
No. of participants in interview / focus group	
Type of user groups/stake holders involved	
Recruitment criteria/rationale applied	

### Introductory Questions

## Questions to start the focus groups / interviews with healthcare professional

**What do you think of the services which are currently provided to patients (with or without help of ICT)?**

**Do you see any advantages or disadvantages in the way services are currently provided?**

**Do you feel the need to improve / change the way services are currently provided (with or without the help of ICT)?**

**Do you know what patients think / feel about the services they are receiving? If yes, what is their opinion?**

**Do you currently make use of ICT e.g. telecare or telehealth equipment / services?**

<sup>1</sup> For the purposes of D2.1 please refer to the technical annex of the patient and informal carer requirements template.



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**In comparison to services provided without the application of ICT do you see any advantages or disadvantages?**

**Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?**

**Could you think of any factors hampering or facilitating the implementation of CareWell services?**

**(Please add further questions here)**

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**Questions for CareWell Integrated Care Coordination Pathways**

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## **Healthcare Professional requirements for CareWell Integrated Care Coordination Pathway (ICCP)**

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**How will existing workflows be adapted for CareWell Integrated Care Coordination Pathway (ICCP)?**

**What changes will healthcare professionals have to make to how they work together?**

**How will responsibility be split between healthcare professionals?**

**What are the advantages of CareWell Integrated Care Coordination Pathway ?**

**What difficulties do healthcare professionals imagine CareWell Integrated Care Coordination Pathway will bring?**

**What functionalities do healthcare professionals need / want for Integrated Care Coordination Pathway service processes?**

**What needs / expectations do healthcare professionals have for ICCP service content?**

**What needs / expectations do healthcare professionals have for Integrated Care Coordination Pathway service usability?**

**What other needs / requirements do healthcare professionals have?**

**(Please add further questions here)**

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**Questions for CareWell PEHP**

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## **Healthcare professionals requirements for CareWell Patient Empowerment and Home-support Pathway (PEHP) services**

**How will existing workflows be adapted for CareWell Patient Empowerment and Home-support services?**

**What changes will healthcare professionals have to make to how they work together?**

**How will responsibility be split between healthcare professionals?**

**What are the advantages of CareWell Patient Empowerment and Home-support services?**

**What difficulties do healthcare professionals imagine CareWell Patient Empowerment and Home-support services will bring?**

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service processes?**

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service content?**

**What needs / expectations do healthcare professionals have for Patient Empowerment and Home-support service usability?**

**What other needs / requirements do healthcare professionals have?**

**(Please add further questions here)**

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## 10.3 ORGANISATIONAL AND FINANCIAL REQUIREMENTS TEMPLATE

Key organisational and financial requirements should be gathered through interviews and / or focus groups. These focus group interviews with key experts will help the project to learn more about the organisational and financial needs regarding the development and implementation of CareWell pathways.

In contrast to the requirements templates for healthcare professionals and patients and informal carers this template doesn't seek to gather the needs of users of the service but the organisational and financial elements which need to be considered for the future service to function well.

Beginning with introductory, ice-breaking question we've already developed some ICCP and PEHP specific questions , however please add your own.

Please specify:

Type of event: interview or focus group	
Date at which the interview / focus group took place	
Venue at which the interview / focus group took place	
Duration of the interview / focus group	
No. of participants in interview / focus group	
Type of user groups/stake holders involved	
Recruitment criteria/rationale applied	



## Introductory Questions

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### Questions to start the focus group interview with key experts

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What do you think of the services which are currently provided to patients (with or without help of ICT)?

How do you evaluate the services which are currently provided to patients (with or without help of ICT)?

Do you feel the need to improve/change the way services are currently provided (with or without help of ICT)?

In which healthcare context do you think ICT applications e.g. telecare or telehealth equipment/services could be used best?

From an organisational and financial perspective do you see any advantages or disadvantages in applying ICT for healthcare purposes?

Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?

Could you think of any factors hampering or facilitating the implementation of CareWell services?

Do you see potentials for improving the envisaged CareWell services?

(Please add further questions)

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**Starter Questions for CareWell ICCP**

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## **Organisational and financial requirements for CareWell Integrated Care Coordination Pathway (ICCP)?**

**How will existing workflows be adapted for CareWell Integrated Care Coordination services?**

**What changes will healthcare providers have to make to how they work together?**

**How will responsibility be split between healthcare provider organisation?**

**What are the incentives for sharing information through CareWell Integrated Care Coordination services?**

**What are the existing barriers to sharing information that are overcome through CareWell Integrated Care Coordination services?**

**How will established consent procedures currently followed by service providers need to be adapted for CareWell Integrated Care Coordination services?**

**What time is required for procuring necessary ICT components or systems for CareWell Integrated Care Coordination services?**

**What other organisational changes are envisaged in order to deliver CareWell Integrated Care Coordination services?**

**(Please add further questions)**

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## 10.4 TECHNICAL REQUIREMENTS TEMPLATE

Key technical requirements should be gathered through interviews and / or focus groups. These focus group interviews with key experts will help the project to learn more about the technical needs regarding the development and implementation of CareWell pathways.

In contrast to the requirements templates for healthcare professionals and patients and informal carers this template doesn't seek to gather the needs of users of the service but the technical elements which need to be considered for the future service to function well.

Beginning with introductory, ice-breaking question we've already developed some ICCP and PEHP specific questions , however please add your own.

Please specify:

Type of event: interview or focus group	
Date at which the interview / focus group took place	
Venue at which the interview / focus group took place	
Duration of the interview / focus group	
No. of participants in interview / focus group	
Type of user groups/stake holders involved	
Recruitment criteria/rationale applied	



## Introductory Questions

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### Questions to start the focus group interview with key technical experts

What do you think of the ICT services which are currently provided to patients?

Do you see any advantages or disadvantages of the way services are currently provided?

Do you feel the need to improve/change the way services are currently provided (with or the help of ICT)?

Which preconditions need to be met for a successful implementation of ICT applications/services in the healthcare context?

If ICT e.g. telecare or telehealth equipment/services are applied what exactly is hampering or facilitating its adequate use?

In comparison to services provided without the application of ICT do you see any advantages or disadvantages?

Regarding the introduction of envisaged CareWell services which advantages or disadvantages do you see?

Could you think of any factors hampering or facilitating the implementation of CareWell services?

Do you see potential of improving the envisaged CareWell services?

(Please add questions)

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## 10.5 LEGAL REQUIREMENTS FOR CAREWELL SERVICES

Legal requirements should be gathered through interviews and / or focus groups. Key areas which should be considered for both the CareWell Integrated Care Coordination service and Patient Empowerment and Home-monitoring service. These legal requirements are to ensure that the proposed CareWell services are legally compliant.

Please specify:

Type of event: interview or focus group	
Date at which the interview / focus group took place	
Venue at which the interview / focus group took place	
Duration of the interview / focus group	
No. of participants in interview / focus group	
Type of user groups/stake holders involved	
Recruitment criteria/rationale applied	

### Operational guidance on how to examine legal, regulatory and contractual implementation requirements

#### Work steps to be conducted for the purposes for legal/regulatory requirements elicitation

- Step 1: Identify individual pieces of legislation and/or regulation (e.g. laws, decrees/ordinances, codes of conduct) that are potentially applicable to the envisaged pilot service. Please consider different governance/regulative levels at which relevant legislation may have been issues, e.g. legislation/regulation enacted at the European, national or regional level. Also, please consider different legislative domains that could have relevance for implementing the CareWell pilot service in your region, e.g. data protection, professional accreditation, responsibility issues, professional conduct / best practices or patients’ rights (please see the list of legal aspects to be considered below.). In particular, please examine whether there is any dedicated legislation concerning telemedicine, telecare or other ICT-applications such as eHealth Records (EHR) or ePrescriptions services in the social/health care domains in your region/country. List all legislation which potentially needs to be addressed in your region/country in regards to the CareWell services. In each case, do not forget to specify the sources from which individual legislation has been identified.
- Step 2: Identify and describe any legal/regulative barriers that need to be considered in implementing the CareWell services.
- Step 3: Identify and describe any operational steps that need to be taken for ensuring that the pilot service and/or particular ICT applications/components to be utilised actually comply with relevant legislation/regulation.
- Step 4: Identify and describe any legal/regulative issues that need to be further investigated or clarified. For each of these issues please describe in what way these will be further investigated/clarified and by when this is expected to be completed.

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## Clinical and device accreditation

**Do existing professional accreditations cover the requirements of the application?**

**Should the professionals be able to complete all the necessary tasks under their existing accreditations?**

**How is the professional liability for engagement in the project supposed to be addressed and insured?**

**Is the liability shared between different professional actors? If yes, which and how?**

**Is there any element of patient/client liability in the project?**

**Do professionals (e.g. clinicians) need to be accredited for delivering services at distance?**

**Will their accreditation be valid at their registration location?**

**Are the systems or devices used in the application subject to rules of certification (e.g. Medical Device Directive CE certification)?**

**If yes, are all devices or systems intended for use in the application certified or do substitutions have to be made?**

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## **Professional liability**

**Will all the actors of the system envisage liability problems?**

**Will the accreditation regulation of each actor of the system envisage liability problems?**

**Will professional liability be insured?**

**Who will be responsible for what in the system (think about every event)?**

**Will there be any element of patient liability involved?**

**Will existing liability insurance mechanisms be sufficient for the application?**

**Will any new insurance or other mechanisms have to be adopted?**

**How will liability between different actors be balanced?**

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## **Information governance/ legal provisions of setting up EHR**

**Are there any legal provisions regarding types and sets of health data of patient's summary?**

**Based on which national/regional legislation EHRs and/or ePrescription services can be set up?**

**Based on which legal regime data can be processed among different entities in the health sector?**

**Have the EU data protection law already be fully implemented in your country? If not, please explain.**

**How will the consent for data collection be obtained (written, oral, proxy)?**

**Will the patient be able to revoke the consent temporarily?**

**How will patients clearly be informed about what data are to be collected, who will get access to the data, and for what purposes?**

**How will patients be given access to the collected data?**

**Will patients be informed if a third party accesses their personal health data?**

**Will patients be able to correct or delete data collected about them in the trial?**

**Who will have access to data and for what purposes? Will the access to data be determined and limited according to roles of health professionals?**

**Who will have access to data in case of an emergency**

**How will access to data be controlled (password, ID, ...)**

**How do you guarantee the traceability and legal non-repudiation of access?**

**With whom will data be shared?**

**Will the data be accessible for secondary use for public health, statistical or research purposes? Is there a legal regime addressing these issues?**

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**Will data be shared among public authorities?**

**Are there legal provisions which either allowing or prohibit the linking of health data with other citizen's data?**

**How will the data be stored, what security measures will be implemented?**

**Will there be different types of patient consent? Which approach (opt-in/opt-out) will be applied?**

**Are there any legal constraints of health data archiving durations? If yes, please specify**

**What measures will be taken to ensure integrity/non repudiation of transferred/shared data?**

**What measures will be taken to ensure accessibility of data by all appropriate parties?**

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## **Occupational codes of practice/patient control and responsibility**

**Are there any national/regional legally and/or morally binding occupational codes of practice in place besides existing international codes of practice (such as The Declaration of Helsinki, The International Code of Ethics of the International Federation of Social Workers, the Good Clinical Practice Directive 2005/28/EC) ?**

**How is the patient's right to be informed guaranteed?**

**How do you guarantee the patient's right to access his/her own data?**

**How do you guarantee the patient's right to rectify his/her own data**

**How do you guarantee the patient's right to object the processing of his/her own data?**

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