

# D6.2 INTERIM PROCESS EVALUATION REPORT – PART 1:

# **WP6 Pilot evaluation**

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# **Document information**

#### Abstract

This deliverable presents the preliminary results of BeyondSilos on a site by site basis. All sites were requested to provide background information on MAST domain 1 and their current enrolment flow-chart and baseline table with information on the recruited participants for MAST domain 2&3.

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#### **Outstanding issues**

Enrolment of participants is not yet complete, so complete baseline analyses will be presented in D6.3.



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This deliverable contains original unpublished work except where clearly indicated otherwise.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



# Executive summary

This deliverable presents the preliminary evaluation results of BeyondSilos on a pilot site level. The deliverable includes description of domain 1 in the MAST, together with a description of domains 2 & 3, and the preliminary results from each pilot site on care-recipient flow and enrolment, aims and objectives and baseline characteristics for the first participants enrolled.

Domain 1: All sites have described Domain 1 in the MAST model "Health and social situation of the care recipients and characteristics of the service" (modified version for integrated care). The description of Domain 1 includes information from all pilot sites on: The health and social situation of the care recipients, quantification of the health and social situation of the care recipients, the management of the health and social situation, the ICT solution supporting integrated care, the technical characteristics of the service, and the requirements for use of the ICT solution.

Domain 2 & 3: With the exception of Northern Ireland and Amadora, all pilot sites have started uploading baseline data to the central database, and have begun the preliminary data analysis of the baseline data. Both Northern Ireland and Amadora are expecting to start data upload by the end of February 2016.

Most pilot sites have had minor delays in the enrolment of care recipients and data upload to the central database. Therefore, this deliverable D6.2 Interim Evaluation Report – Part 1 only includes baseline results for participants enrolled as of mid-January 2016.

An overall view of the preliminary results from domains 2&3 is presented in section 4.2 Overall comparison across pilot sites.



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# 1 Introduction

## **1.1** Purpose of document

Deliverable D6.2 Interim Evaluation Report describes the preliminary results of BeyondSilos at a local pilot site level. Due to the large amount of information included, the document is divided into two separate documents:

- D6.2A Interim Evaluation Report Part 1: Background description of pilot sites and reporting of quantitative data collection of baseline data based on the MAST methodology.
- D6.2B Interim Evaluation Report Part 2: Qualitative data collection on perspectives of care recipients and professionals regarding ICT supported integrated care

This deliverable D6.2A Interim Evaluation Report – Part 1, provides details on MAST Domain 1 (Health and Social problem and characteristics of the application) and Domains 2&3 (Safety, Clinical and Social effectiveness). Full results will be included in the final overall evaluation report D6.3.

Preliminary results for MAST Domain 4 (Patient Perspective) and Domain 6 (Organisational Aspects) are presented in D6.2B Interim Evaluation Report – Part 2. Preliminary results for Domain 5 (Economic aspects) will be presented in deliverable D7.4 Interim report on exploitation activities and results on Domain 7 (Socio-cultural, ethical and legal aspects) will be included in the final evaluation deliverable D6.3.

# **1.2** Structure of document

This deliverable consists of:

- Section 2: A description of the analysis and reporting of data within relevant MAST domains
- Section 3: A description of domain 1 in the MAST model from each pilot site including a description of the health and social problems and characteristics of the ICT application
- Section 4: A description of the framework of the expected data collection for domain 2 and 3 of the MAST model concerning the safety, clinical and social effectiveness of the ICT application.
- Section 5: Conclusion on status and input of the evaluation

# 1.3 Glossary

ADA	American Diabetes Association
ADL	Activity of Daily Living
CHF	Congestive Heart Failure
COPD	Chronic obstructive pulmonary disease
CR	Care recipient
CVD	Cardiovascular disease
DALYs	Disability-adjusted life year
EASD	The European Association for the Study of Diabetes
EUnetHTA project	European network for Health Technology Assessment
GOLD	Global Initiative for Chronic Obstructive Lung Disease



GP	General Practitioner
HbA1c	Glycated haemoglobin
НСР	Health Care Provider or Health Care Professional
НТА	Health Technology Assessment
IADLs	Instrumental activities of daily living
ICP-Short	Short-term pathway
ICP-Long	Long-term pathway
ІСТ	Information Communication Technology
IDF	The International Diabetes Federation
MAST	Model for Assessment of Telemedicine
NCDs	Non-communicable diseases
OGTT	Oral Glucose Tolerance Test
QoL	Quality of life
Renewing Health	REgioNs of Europe WorkINg toGether for HEALTH
SCP	Social care provider
TSCP	Third Sector Care
WHO	World Health Organisation



# 2 Analysis and reporting of data within relevant MAST domains

# 2.1 Introduction

The structure of the reporting guideline follows the MAST structure (see Figure 1)<sup>1</sup>. However, since BeyondSilos examines ICT solution for integrated care between health and social sectors, the social aspect has been added to the MAST model. Any changes in the MAST model are <u>underlined</u> and in *italics* in the model below.

Since BeyondSilos is at the start of the data collection phase, this deliverable D6.2 Interim Evaluation Report will only include preliminary results at a local pilot site level from BeyondSilos in relevant domains. The deliverable presents the minimum level of analyses that all pilots should carry out, mainly on the basis of the minimum dataset that all pilots collect. However, pilots are free to specify additional data to be collection for specific local health care, social care or integrated care initiatives or other additional studies.

The pilot sites will deliver preliminary results for the following MAST domains: domain 1, domain 2&3, domain 4 and domain 6. Preliminary results for domain 5 Economic aspects will be presented in deliverable D7.4 Interim report on exploitation activities.

The structure of each domain is the same:

- Introduction, including definition of the domain and relation to the minimum data set.
- Reporting of results, description of the information, tables and results performed by each pilot site.

# 2.2 Short description of MAST

MAST was developed in 2010 through user and stakeholder workshops and on the basis of a systematic literature review. If the objective of an assessment of telemedicine applications is to describe effectiveness and contribution to quality of care and to produce a basis for decision making, then MAST defines the relevant assessment framework fulfilling this objective as a multidisciplinary process which summarises and evaluates information about the medical, social, economic and ethical issues related to the use of telemedicine in a systematic, unbiased, robust manner.

This statement of principle is based on the definition of HTA in the EUnetHTA project. Key concepts are "multidisciplinary" and "systematic, unbiased and robust". The first concept implies that the assessments should include all important outcomes of the applications for patients, clinicians, healthcare institutions and society in general. The others imply that assessments should be based on scientific studies and methods and on scientific criteria for quality of evidence.

In practice, MAST implies that an assessment of a telemedicine application should include three elements.

- Firstly, the assessment must start with preceding considerations in order to determine whether it is relevant for an institution at a given point in time to carry out the assessment. This step involves assessment of the legal aspects, the maturity of the technology and the number of patients; this will not be described further in this guide (see instead Kidholm et al. 2012).
- Secondly, after the preceding considerations, the multidisciplinary assessment is carried out in order to describe and assess the different outcomes of the telemedicine application. As shown in Figure 1 below, the outcomes and description of patients and the telemedicine application can be

<sup>&</sup>lt;sup>1</sup> Kidholm K, Pedersen CD, Jensen LK, Ekeland AG, Bowes A, Flottorp S, Bech M. A model for assessment of telemedicine applications – MAST. International Journal of Technology Assessment in Health Care, 28:1, January 2012, 44-51.



divided into seven domains based on the EUnetHTA Core Model and results from stakeholder workshops. In the sections below, analysis of data and reporting of results within these seven domains will be described further.

• Finally, in relation to the description of the outcomes, an assessment should also be made of the transferability of the results to other settings or countries.



Any words highlighted and underlined are an addition to the MAST model for the purpose of the BeyondSilos project.

Figure 1: The elements in MAST

# 2.3 Background

The report is based on a number of documents:

- The Renewing Health Guideline on analysis and reporting of results from the pilots in Renewing Health, September 2013.
- MAST Manual.
- A detailed description of MAST (Model for Assessment of Telemedicine applications) and the seven domains included in MAST can be found in the MAST-manual (2010)<sup>2</sup>. A short description can be found in Kidholm et al. (2012).
- Deliverable D6.1 BeyondSilos Evaluation Framework, 2014.

Each pilot site has been given an elaborate guideline on how to report on the included domains for this deliverable. A template for each domain has been provided in the guidelines. Furthermore, all included domains have been discussed and agreed on at the General Assembly meeting held in Salerno, Italy, on 1<sup>st</sup> October 2015, as well as in following telco meetings attended by each of the pilot sites.

<sup>&</sup>lt;sup>2</sup> <u>http://www.renewinghealth.eu/project-overview/overview/assessment-method</u>



# 3 Domain 1: Description of the health and social problems and characteristics of the application

# 3.1 Introduction

As the MAST Manual describes, the first domain includes a description of the health and social problem of the care recipient and of the application being assessed including description of the current use. In BeyondSilos, this will include a description of the social needs of the care recipient, a summary of the ICT solution for integrated care (a full description can be found in deliverable D4.2 BeyondSilos Prototype system), as well as a description of the integration between sectors (health / social / care recipient / volunteers / etc.). Thus, the content of this domain serves as a description of the background and context in which the study is carried out, and helps to understand the perspective from which the assessment is performed. It iritates me

Description of the geographical context and the health and social care setting is relevant for the construction of economic and/or organisational models in order to assess the impact of, for example, the future deployment of the application under investigation, or the promotion of its use, etc. In addition, in a later stage of the assessment, the information provided in this domain could be used for evaluation and discussion of the generalisability of the reported results.

# **3.2** Reporting of results

There are three main topics included within Domain 1; the third topic has been added by the evaluation team in order to include integrated care in the MAST model:

- 1. Description of the target diseases or health problem and their social impact.
- 2. Description of the ICT solution, explaining its use and technical characteristics.
- 3. Description of integrated care, including integration between sectors, explaining its current pathways and how this is expected to change with the new service.

The reporting will follow the headings listed below when reporting information for domain 1:

- The health and social situation of the region.
- Quantification of the health and social situation.
- Management of the health and social situation (current and new care).
- The ICT solution supporting integrated care (including technical characteristics of the service).
- Requirements for use of the ICT solution.
- A case description of the local BeyondSilos service.

As the pilot sites have agreed to enrol only care recipients with the presence of heart failure, stroke, COPD, fractures or diabetes as their main disease, domain 1 begins with a general description of these diseases and a general estimate of the quantification of the burden of the diseases. Since another important inclusion criterion for the BeyondSilos project is the presence of social needs, a general description of social needs follows the general description of the included diseases. Thereafter, each pilot site describes the rest of the themes included in Domain 1 at an individual level tailored to their pilot site. Each pilot site ends the description of domain 1 with a case description of a typical care recipient included in the BeyondSilos project.



# **3.3** General description of the health situation of the care recipients

The following section gives a general description of the main diseases included in the BeyondSilos project, and a general estimate of the quantification of the burden of the diseases. For a complete overview on the topic burden of disease please view "The global burden of disease: 2004", issued by the World Health Organisation<sup>3</sup>.

## 3.3.1 Chronic obstructive pulmonary disease (COPD)

Chronic obstructive pulmonary disease (COPD) is an umbrella term for a number of lung diseases that cause difficulties in proper breathing. Three of the most common characteristics are emphysema, chronic bronchitis, and chronic asthma that is not fully reversible. These conditions can occur separately or together. The main symptoms are breathlessness, chronic cough, and sputum production. Cigarette smokers and ex-smokers are most at risk. COPD used to be more common in men, but the disease is quite evenly spread across the sexes; women and men now smoke in equal numbers. Typically, COPD develops so slowly that the person does not realise their ability to breathe is gradually becoming impaired. The structural damage occurs before the symptoms are severe enough to notice.

Symptoms include: breathlessness after exertion; in severe cases, breathlessness occurs even at rest; wheezing; coughing; coughing up sputum; fatigue; cyanosis.

A person with COPD is at increased risk of a number of complications, including: chest infections and pneumonia, respiratory insufficiency with hypoxaemia / hypercapnia, heart failure, anxiety and depression, risks of sedentary lifestyle and osteoporosis (as a side effect of the corticoid treatment), collapsed lung.

The 2011 update of the GOLD guidelines<sup>4</sup> acknowledges that acute episodes of exacerbation in patients with COPD constitute a major deleterious factor negatively modulating several dimensions of the disease, namely: deteriorates patient's quality of life; increases the use of healthcare resources; accelerates COPD progress; and it has a negative impact on patient's prognosis. Moreover, it has been demonstrated that hospital admissions due to severe episodes of COPD exacerbation constitute the most important factor determining disease burden in the health system. Consequently, early detection, correct therapy / follow-up and self-management of COPD exacerbations, as well as policies to prevent unplanned hospital admissions of COPD patients due to acute episodes of the disease, seem to constitute the two pivotal priorities in COPD management.

#### **3.3.1.1** Burden of the disease

COPD is a highly prevalent chronic condition affecting approximately 9% of the adult population (>45 yrs). In Europe, the disease is mainly caused by tobacco smoke in susceptible subjects, but air pollution is often involved (prolonged exposition to pollutants). It has a high degree of under-diagnosis (approximately 70%), and it shows an elevated degree of heterogeneity. Organisation of healthcare in COPD patients requires a proper assessment of risk and subsequent generation of stratification criteria, and a high degree of adherence to the correct therapy.

The disease is currently the fourth cause of death worldwide with a trend to increase during the next few years. It is estimated that COPD will be the third cause of disease in 2020. The disease burden on the health system is mainly due to hospital admissions and complications associated with frequent co-morbid

<sup>&</sup>lt;sup>3</sup> http://www.who.int/healthinfo/global\_burden\_disease/2004\_report\_update/en/

<sup>&</sup>lt;sup>4</sup> Vestbo J, Hurd SS, Agustí AG, Jones PW, Vogelmeier C, Anzueto A, Barnes PJ, Fabbri LM, Martinez FJ, Nishimura M, Stockley RA, Sin DD, Rodriguez-Roisin R. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: GOLD executive summary. Am J Respir Crit Care Med. 2013.15;187(4):347-65



conditions, including highly prevalent non-communicable diseases (NCDs) such as cardiovascular disorders and type 2 diabetes mellitus. COPD is part of the main chronic disorders of the WHO's programme for NCDs which is one of the health priority issues at worldwide level, as shown by the United Nations General Assembly devoted to the topic in 2011<sup>5</sup>. A recent update on the high impact of COPD in terms of deaths, years of life lost, years lived with disability and DALY's has recently (2013) been reported in the New Engl J of Med<sup>6</sup>.

# 3.3.2 Diabetes Mellitus (type 1 and type 2)

Diabetes Mellitus is a syndrome where the blood glucose concentration is increased. There are two types of diabetes:

- Type 1 is caused by a lack of insulin production, partly due to genetic factors. The elevated blood glucose concentration can be lowered by injecting insulin. The injected insulin allows glucose in the blood to go into the cells, where it is needed.
- Type 2 is caused by a relative deficit of insulin, with decreased cell sensitivity. Type 2 diabetes can be hereditary, and commonly occurs in connection with overweight / obesity. Type 2 diabetes is the most common type of diabetes. Because of an unhealthy lifestyle lead by many people, it is estimated that an enormously increased number of people will suffer from the disease in the future.

Diabetes mellitus type 2 represents about 90% of diabetes cases, while the remaining 10% is mainly due to diabetes mellitus type 1 and to gestational diabetes<sup>7</sup>. Since most of the care recipients enrolled in the BeyondSilos project because of a diabetes diagnosis suffer from type 2 diabetes, the following description will focus on this type.

Diabetes mellitus type 2 is a metabolic disease characterised by insulin resistance due to multifactorial factors. Therefore, diabetes mellitus causes a persistent instability of blood glycaemic level, with various levels of hyperglycaemia (in a very wide range); hypoglycaemia is usually caused by hypoglycaemic agents.

First usual symptoms for diabetic patient are polyuria (frequent urination), polydipsia (increased thirst), polyphagia (increased hunger) and weight loss. Other symptoms commonly present at diagnosis are: blurred vision, itch and peripheral neuropathy. Often diabetes is discovered with the occurrence of a cardiovascular event (myocardial infarction-angina; stroke / TIA; etc.).

Lots of people are not affected by symptoms in the first years, and the diagnosis is made only through routine tests. In the case of very high glycaemic levels, as an extreme condition patients with diabetes mellitus type 2 may suffer from hyperglycaemic hyperosmolar nonketotic coma (i.e. very high level of sugar in blood, associated with a decrease of consciousness and hypotension level); death rate is very high, particularly in old age.

The clinical diagnosis of diabetes mellitus type 2 is normally anticipated by an asymptomatic phase of about seven years<sup>8</sup>, during which hyperglycaemia causes deleterious effects at target tissues level, so that at the moment of clinical diagnosis the complications of the disease are already present.

<sup>&</sup>lt;sup>5</sup> 2011 High Level Meeting on Prevention and Control of Non-Communicable Diseases. General Assembly. New York. 19-20 September 2011. "Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases". Document A/66/L.1. http://www.un.org/en/ga/ncdmeeting2011/

<sup>&</sup>lt;sup>6</sup> Murray CJ, Lopez AD. Measuring the global burden of disease. N Engl J Med. 2013;369(5):448-57

<sup>7</sup> WHO 2012

<sup>&</sup>lt;sup>8</sup> "Standard italiani per la cura del diabete mellito tipo 2" – Società Italiana di Medicina Generale, Associazione Medici Diabetologici – Società Italiana di Diabetologia – 2011 Infomedica, Formazione & Informazione Medica



The WHO recognises diabetes (type 1 and type 2) after the detection of high glucose levels and the presence of typical symptoms. Diabetes can be diagnosed through one of the following:

- Glycaemia on fasting ≥126 mg/dl on a sample taken at about 8 a.m. after at least eight hours of fasting.
- Glycaemia ≥ 200 mg/dl 2 hours after 75 g glucose oral glucose tolerance test (OGTT)8.

In 2009, an international committee of experts, including representatives of the American Diabetes Association (ADA), the International Diabetes Federation (IDF), and the European Association for the Study of Diabetes (EASD), recommended a level of HbA1c  $\geq$  6,5% to be used for diabetes diagnosis. ADA adopted this recommendation in 2010.

For a comprehensive review, see: International Diabetes Federation (IDF) Global Guideline for Managing Older People with Type 2 Diabetes, 2013.<sup>9</sup>

Once the pathology is diagnosed, the most important value to monitor the clinical course of diabetes is the glycosylated haemoglobin (HbA1c); the higher the glycaemia is, the higher the glycosylated haemoglobin levels will be. As the haemoglobin is carried into red blood cells having an average life of 120 days, the HbA1c value reflects the control of glucose levels in the three months before the analysis. Generally, a value lower than 6.1% is considered normal. The typical HbA1c value in diabetic patients is higher than 7%; diabetes is well compensated / controlled if values are equal to or lower than 6.5%<sup>10</sup>.

The persistence over the years of hyperglycaemia determines the relevant complications:

- Cardiovascular diseases, in large vessels (macroangiopathy as coronaries) and micro vessels (microangiopahy as in the retina); hypertension.
- Metabolic disturbances, for example hyperlidemia, particularly hypertriglyceridemia.
- Diabetic nephropathy, which affected 20-40% of diabetic patients; today it is the main cause of nephropathy in terminal phase.
- Retinopathy, strictly correlated to the duration of diabetes, is today the main cause of new cases of blindness in adults aged 20 to 74 years.
- Neuropathy that generally affects distal sensory nerves, altering the perception of vibration, temperature and pain in feet and hands.
- Ulceration that leads to foot amputation.

Since these complications structurally damage many organs, diabetes mellitus type 2 is a chronic disease associated with a life expectancy that is 10 years lower than average.

A certain number of factors correlated to lifestyle are known to be linked to the development of diabetes mellitus type 2, among which are over-nutrition with consequent overweight and obesity (defined by a body mass index higher than or equal to, respectively, 25 or 28 kg/m<sup>2</sup>), lack of physical exercise, bad diet (consumption of too much sugar or saturated fats). Diabetes is one of the most important cardiovascular risk factors, and the prevalence of other cardiovascular risk factors is very high in the diabetic population (hypertension, hyperlidemia, etc.). Moreover, there are people predisposed to the development of diabetes mellitus type 2 on a genetic basis (people with a family history of diabetes). Women with previous events of gestational diabetes also have an increased risk. In addition to this, some drugs can increase blood sugar levels (typically glucocorticoids and thiazides).

<sup>&</sup>lt;sup>9</sup> http://www.idf.org/guidelines-older-people-type-2-diabetes

Rossana de Lorenzi, Cristina Gritti, "Verso il primo farmaco ricombinante", European Molecular Biology Laboratory 2007



Finally, recent evidence shows that there might be a link between bad control of diabetes and worsening, if not causing, of cognitive impairment in the elderly.

#### **3.3.2.1** The burden of the disease

In 2010, about 285 million people in the world were estimated to suffer from diabetes mellitus type 2; this represents about 90% of diabetes cases, and about 6% of the world adult population. Traditionally considered as an adult disease, diabetes mellitus type 2 is now being diagnosed more frequently in children, in parallel with higher obesity rates<sup>11</sup>.

Diabetes complications can be extremely disabling, and compromise the functioning of essential organs: heart (myocardial infarction, heart diseases); kidneys (renal failure with the need for dialysis or transplantation); other blood vessels (peripheral and/or cerebral arteriopathy with the consequence of gangrene and stroke); eyes (glaucoma, retinopathy, blindness, etc.). Personal and social consequences of diabetes are therefore a progressive loss of personal autonomy and of work skills, reduction of social contacts, more frequent need for care and assistance, even at home, and frequent hospital care. The personal consequences can also include depression, anxiety, and other problems in the area of mood and brain-body functioning. All these problems increase with advancing age.

Good treatment and control of the disease can reduce both the personal and social consequences for the individual<sup>12</sup>.

# **3.3.3** Cardiovascular diseases (CVDs)

Cardiovascular diseases are the largest cause of deaths worldwide<sup>13</sup>. Hypertension, tobacco smoking, hyperlipidemia, obesity (as a result of inappropriate diet and physical activity), are the main modifiable risk factors of CVDs. The leading unmodifiable causes are age and genetic predisposition. CVDs are largely preventable; population-wide measures and improved access to individual healthcare interventions can result in a major reduction in the health and socio-economic burden. These interventions, which are strongly evidence based and cost effective, are described as best buys<sup>14</sup>. Although a large proportion of CVDs are preventable, they continue to rise mainly because preventive measures are inadequate, life styles remain incorrect, and correction of risk factors is largely insufficient.

#### **3.3.3.1** Burden of the disease

It is reported that more than 17 million people worldwide died from CVDs in 2008. Of these deaths, more than 3 million occurred before the age of 60, and could have largely been prevented. Out of the 17.3 million cardiovascular deaths in 2008, heart attacks were responsible for 7.3 million, while strokes were responsible for 6.2 million deaths. Premature deaths from CVDs range from 4% in high-income countries to 42% in low-income countries, leading to growing inequalities in the occurrence and outcome of CVDs between countries and populations. Deaths from CVDs have been declining in high-income countries over the past two decades, but have increased at a fast rate in low- and middle-income countries.

<sup>11</sup> International Diabetes Federation Data - 2010

<sup>&</sup>lt;sup>12</sup> http://changingdiabetesbarometer.com/docs/Diabetes%20den%20skjutle%20epidemic%20og%20konsekvenserne %20for%20Danmark.pdf

<sup>&</sup>lt;sup>13</sup> WHO, World Heart Federation., & World Stroke Organisation. (2011). Global atlas on cardiovascular diseases prevention and control. Eds: Mendis, S., Puska, P Norrving, B.

http://www.who.int/cardiovascular\_diseases/publications/atlas\_cvd/en/index.html (last checked 4/11)
 <sup>14</sup> WHO (2011). Global Status Report on Non-communicable Diseases (NCDs). 2010 ed Alwan, A.

http://www.who.int/nmh/publications/ncd\_report2010/en/ (last checked 23/11)



## 3.3.4 Stroke

Stroke is a cerebrovascular disease (ischemia-infarction or intracranial haemorrhage) that causes neurological disability. Ischemia-infarctions constitute 85-90% of the strokes in western countries, while 10-15% is due to intracranial haemorrhages. The former consists of a reduction in blood flow (ischemia) lasting long enough to produce infarction in the brain tissue, whereas haemorrhages are the consequence of a disruption in blood vessels causing intracranial bleeding.

Stroke refers to the abrupt onset of a focal neurological deficit. The symptoms and signs vary depending on the location and the extent of the brain injury: the hallmark presentation is a weakness of one side of the body (hemiparesis), but also hemisensory loss, visual deficits (hemianopsia), speech disorders (aphasia, dysarthria), swallowing problems (dysphagia), dizziness, gait disorders, changes in behaviour, among others. The deficit may remain fixed, may improve or may progressively worsen.

In the acute phase the treatment is focused on revascularisation (thrombolysis), cardiovascular control, such as hypertension, and metabolic control (hyperglicemia-diabetes), which are also the main risk factors for stroke, along with hypercholesterolemia. After the event, rehabilitation plays a crucial role. It is mandatory to initiate physical therapy from the start, as it has been demonstrated to improve the midterm and long-term functional prognosis. Indeed, once the acute stage of the illness has passed, the consequent degree of disability and frailty is the main concern. This will depend on the extension and kind of stroke, age, the functional independence at discharge, the comorbidities, but also on the rehabilitation programme and social support<sup>15</sup>. The prevention of recurrences is the other main goal of therapy, which can be obtained by controlling risk factors (primarily hypertension).

#### **3.3.4.1** Burden of the disease

Stroke represents the third most common cause (10% of deaths overall) in developed countries, after coronary heart disease and cancer. Moreover, stroke is the first cause of physical disabilities. Worldwide, 15 million people suffer a stroke each year; one third die and one-third are left permanently disabled. The WHO predicts that disability-adjusted life years (DALYs) lost to stroke will rise from 38 million in 1990 to 61 million in 2020<sup>16</sup>.

In Europe, the incidence of stroke varies from 101-239 per 100,000 inhabitants in men and 63-159 per 100,000 inhabitants in women<sup>17</sup>. The estimated cost in Europe in 2010 was roughly 64.1 billion  $\in$ <sup>18</sup>. Although the incidence of stroke is declining in developed countries, largely due to efforts to lower blood pressure and reduce smoking, the overall rate remains high due to the aging of the population.

The incidence of stroke increases with age and affects many people in their "golden years". Half of people suffering from stroke are over 75 years-old, and one third are over 80. Thus, the impact on dependency (lack of personal autonomy, assistance at home, correct nutrition, control of metabolic disorders, etc.)

<sup>&</sup>lt;sup>15</sup> Factors predictive of stroke outcome in a rehabilitation setting. Ween JE, Alexander MP, D'Esposito M, Roberts M. Neurology 1996; 47(2): 388-92

<sup>&</sup>lt;sup>16</sup> The atlas of heart disease and stroke, WHO 2004. http://www.who.int/cardiovascular\_diseases/en/cvd\_atlas\_15\_burden\_stroke.pdf (Mackay J, Mensah G: The Atlas of Heart Disease and Stroke. Geneva, Switzerland, World Health Organization, 2004)

 <sup>&</sup>lt;sup>17</sup> Incidence of stroke in Europe at the beginning of the 21st century. Europena Registers of Stroke (EROS)
 Investigators, Heuschmann PU, DiCarlo A, Bejot Y, Rastenyte D, Ryglewicz D, Sarti C, Torrent M, Wolfe CD.
 Stroke 2009 May; 40(5): 1557-63.

<sup>&</sup>lt;sup>18</sup> Gustavsson A, Svensson M, Jacobi F, et al. Cost of disorders of the brain in Europe 2010. Eur Neurpsychopharmacol 2011;21:718-779.



and the social consequences, mostly due to disability, also to anxiety, depression, social isolation, require in this group of patients intensive interventions<sup>19</sup>.

## 3.3.5 Hip Fractures

Hip fracture is a break in the upper quarter of the femur (thigh), close to the hip joint. They occur most commonly from a fall or from a direct blow to the side of the hip. Some medical conditions, such as osteoporosis or cancer, can weaken the bone and make the hip more susceptible to breaking. In severe cases, it is possible for the hip to break with the patient merely standing on the leg and twisting.

Osteoporosis is a disease consisting of the thinning of the bones, with a reduction in bone mass due to depletion of calcium and bone proteins. Thus, it predisposes to fractures (hip, wrist, spine), which are often slow and difficult to heal. Osteoporosis is more common in older adults, particularly in post menopausal women (due to the accelerated bone loss), and in people taking steroidal drugs.

Hip fractures, in particular, have a strong negative effect on activities of daily living and consequently on quality of life. In older people, they decrease their life expectancy and independence. Taking into account that older population usually presents other health problems (diabetes, heart failure, COPD, steroid therapy, ...) and is already at more risk of falling due to frailty (reduced vision, reduce of strength, balance problems, ...), the prognosis for rehabilitation and recovery after the injury is challenging. It must also be taken into account that the event could recur, mainly due to other falls, more frequently in very old subjects.

#### **3.3.5.1** Burden of the disease

Osteoporosis is a major public health problem because of its association with fragility fractures, among them those affecting the hip. It is estimated there were 1.7 million hip fractures worldwide in 1990. With the rising life expectancy in the developed countries, the predicted incidence for the year 2050 is 6.3 million<sup>20</sup>.

Incidence of hip fractures varies between North and South Europe. After age adjustment, hip fractures are more common in Scandinavia with the highest reported incidence worldwide: (920 per 100,000 inhabitants in women and 399.3 per 100,000 inhabitants in men). On the other hand, in Southern European countries the incidence is almost seven-fold lower<sup>21</sup>.

At any age, hip fracture is approximately twice as common in women as in men<sup>22</sup>. 90% of cases occur in people over 50 years old, rising in incidence dramatically with increasing age<sup>23</sup>. In this context, hip fracture is associated with significant morbidity and mortality (20-24% in the first year after discharge)<sup>24</sup>. Loss of function is important with 40% of cases unable to walk independently after one year of follow-

<sup>&</sup>lt;sup>19</sup> Factores pronósticos de recuperación funcional en pacientes muy ancianos con ictus. Estudio de seguimiento al año. JJ Baztan, DA Pérez-Martínez, M.Fernández-Alonso, R Aguado-Ortego, G Bellando-Álvarez, AM de la Fuente González. Rev Neurol 2007; 44(10): 577-583.

<sup>&</sup>lt;sup>20</sup> Cooper C, Campion G, melton III LJ. Hip fractures in the elderly: a world-wide projection. Osteoporosis Int 1992;2:285.

<sup>&</sup>lt;sup>21</sup> Johnell O, Gullberg B, Allander E, Kanis JA. The apparent incidence of hip fracture in Europe: A study of national register sources. MEDOS Study Group. Osteoporos Int. 1992;2:298–302.

<sup>&</sup>lt;sup>22</sup> Jacobsen SJ, Goldberg J, Miles TP, et al. Hip fracture inci- dence among the old and very old: a populationbased study of 745,435 cases. Am J Public Health 1990;80:871-3

<sup>&</sup>lt;sup>23</sup> Cumming RG, Nevitt MC, Cummings SR. Epidemiology of hip fractures. Epidemiol Rev 1997; 19(2): 244-257

<sup>&</sup>lt;sup>24</sup> Leibson CL, Tosteson AN, Gabriel SE, et al. (2002) Mortality, disability, and nursing home use for persons with and without hip fracture: a population-based study. J Am Geriatr Soc 50:1644.



up<sup>25</sup>. It is generally assumed that the high burden on the medical and social system can be lowered by developing multidisciplinary care pathways for those patients.

# **3.4** General description of the social situation of the care recipients

This section outlines a synthesised profile of social issues. This complements the information on the main diseases above, bearing in mind that the Project addresses a comprehensive view of the person (multidimensional assessments with a whole life approach), combining medical (health) and social care interventions, supported through personalised care programmes that include actions in both domains (silos).

# 3.4.1 Social needs

In BeyondSilos, care recipients are recruited because of the presence of both health and social needs. This means that besides suffering from a main disease (heart failure, COPD, diabetes, stroke or fractures) plus other comorbidities, they are having difficulties with some "normal daily activities", such as shopping, preparing food, etc. The social needs represent an additional need for the person / patient, other than the management of the diseases, and they contribute in a relevant way to the course of the pathology (e.g. poorly regulated nutrition dramatically worsens any organ failure). In a reciprocal way, the drop in health status, for example if the disease is not being controlled properly, can adversely affect functional abilities in the performance of daily tasks, so that the person can progressively worsen his/her ability to live in an independent manner, and therefore enters the sphere of social support needs.

These persons are quoted as having "complex needs", that require a whole life (holistic) approach, i.e. the delivery of both healthcare and social services, that aim simultaneously, in a coordinated way, to control the clinical conditions (avoiding recurrences, decline) and living performances (by means of possible social support). These are the main characteristics and requirements of integrated care.

In summary, integrated care requires joint, well coordinated care interventions, with a strict cooperation between staff, with global care actions that are necessarily multidisciplinary, multi professional, and multi sectorial.

In BeyondSilos, social needs are assessed by selected indicators:

- 1. The main life activities for independent living are measured by IADL (instrumental activities in daily life)<sup>26</sup>.
- 2. The performance in activities of daily living  $(ADLs)^{27}$  measured by the Barthel scale<sup>28</sup>.
- 3. Measurement of actually social care provided to each care recipient, though this does not necessarily correspond to what they actually need<sup>29</sup>.

#### Assessment of functional capabilities

Functional capabilities refer to the possibility of performing independent living tasks. The concept of *functional* disability distinguishes basic daily activities that are necessary to function personally and in the

<sup>&</sup>lt;sup>25</sup> Magaziner J, Simonsick EM, Kashner TM, et al. (1990) Predictors of functional recovery one year following hospital discharge for hip fracture: a prospective study. J Gerontol 45:M101.

<sup>&</sup>lt;sup>26</sup> Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. The Gerontologist, 9(3), 179-186.

<sup>&</sup>lt;sup>27</sup> Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The Index of ADL: A standardized measure of biological and psychosocial function. JAMA 1963 Sep 21;185:914-919

 <sup>&</sup>lt;sup>28</sup> Mahoney FI, Barthel D. "Functional evaluation: the Barthel Index." Maryland State Medical Journal

<sup>1965;14:56-61</sup> 

<sup>&</sup>lt;sup>29</sup> See Appendix A.



community from other major social roles, such as work disability or social interactions. Functional disabilities are divided into activities of daily living (ADLs), which include basic activities of hygiene and personal care, and IADLs, which include basic activities necessary to reside in the community.

In social sciences, ADLs refer to the basic tasks of everyday life, such as eating, bathing, dressing, toileting, and moving around. When people are unable to perform these activities, they need help in order to cope, either from other human beings, or using mechanical devices, or both. Although persons of all ages may have problems performing ADLs, prevalence rates are much higher for the elderly than for the non-elderly. Within the elderly population, ADL prevalence rates rise steeply with advancing age, and are especially high for persons aged 85 and over.

Measurement of ADLs is critical, because they have been found to be significant predictors of mortality, use of health care services (hospital or physician services, GPs visits, home care, etc), and admission to a nursing home.

ADLs do not measure all activities necessary for independent living. To complete the assessment, IADLs were developed (Lawson and Brody, 1969). IADLs cover activities that are more complex than those needed for ADLs, such as handling personal finances, meal preparation, shopping, travelling, doing housework, using the telephone, and taking medications. In general, IADL disabilities represent less severe dysfunction than ADLs.

# 3.5 Integration level

In an attempt to describe the level of integration between sectors or/and actors involved in the care pathways, the Medical Coordinator together with the evaluation team represented by RSD and pilot sites have adopted a shared pragmatic approach to describe, in a visual way, the reality at the start and the progression of integration that occurred throughout the project. Each pilot site has produced a table reporting a self-assessment of the interactions and integration within and between actors. These tables are shown below in the sections 3.n.3 "Management of the health and social problems" of each pilot site. The tables show the status of interactions at the beginning of the project, and the changes that occurred up to the time of this interim evaluation report (15<sup>th</sup> February).

The matrix has been filled out by the project manager of each site and reflects the interactions perceived by the manager and the local team.

Note that the methodology is based on a self-assessment of the degree of integration and interaction, graduated using an agreed scale, as described below (scores: None, Low, Medium, High, Unchanged, Added value and NA). Each graduation of interaction between sectors is followed by a short description from the pilot site. Any changes that have occurred in the interactions between actors have been **highlighted and underlined** in the table.

In Appendix C, the Medical Coordinator, together with the pilot sites, has developed a scoring system giving summarised results for the interaction tables for each pilot sites.

Scoring items for the self-assessment:

- None: No interaction between sectors/actors (including spontaneously or informally interaction).
- Low: Only spontaneous or informal integrated practices. No formal agreements in place.
- **Medium**: Some formal agreements/rules are in place. However, interactions between sectors/actors occur in routine practice more spontaneously and informally (more than for low interaction) rather than planned.
- **High**: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.



- **Unchanged**: This only applies when the level of integration remained unchanged, irrespective from the starting point (has remained unchanged because of, for example, lack of time, no strategy-commitment ad hoc, good starting value, etc.).
- **Added value**: This only applies when an improvement occurred but with minor changes (e.g. without new formal protocols in place) vs starting point. A short description can be used.
- NA : not applicable

# 3.6 Domain 1: Badalona

# 3.6.1 Description of the health and social problem

In Badalona Serveis Assistencials (BSA), we will include care recipients with COPD, type 2 diabetes, cardiovascular diseases hip fractures and stroke in the BeyondSilos evaluation. For a general description of the diseases and social situation please see section 3.3 and 3.4.

BSA provides health & social care services in the suburban area of Barcelonés Nord, including the cities of Badalona (the third most populated in Catalonia) and the surrounding smaller towns of Montgat & Tiana. The overall number of inhabitants BSA takes care of is ~430,000.

A specific tool from our database allows us to stratify users according the complexity of their pathologies. At the top of the pyramid, we classify those patients with chronic complex comorbidities, including diabetes, COPD, heart failure or other cardiovascular diseases. We estimated 20% of them as having need of social support: home care assistance is then provided. When one of these patients is admitted into hospital at least twice in the same year, a specific integrated programme is implemented: a team composed of a case manager nurse and a referring physician coordinate his/her medical and social needs, trying to prevent rehospitalisation.

## 3.6.2 Quantification of the burden of disease / health problem and social problem

#### Chronic Obstructive Pulmonary Disease (COPD)

In Spain, the prevalence of COPD is around 10% for patients between 40 and 80 years old. Deaths caused by COPD are 18,000 per year, which means this is the fifth death cause for men in Spain and seventh cause of death among women.

In Catalonia, among the overall hospital admissions in 2008 (122.5 people per 1,000 inhabitants), 13 per 1,000 (10.6%) were due to respiratory diseases, 2.5 per 1,000 (2%) specifically related to COPD. In the same year, they represented the third cause of death in both men and women (10.26% of overall deaths). That is why the *Pla de Salut de Catalunya* 2011-15 included COPD among the five chronic diseases responsible for 78% of deaths and 53% of expenses from the general budget of the Catalonian Public Health System.

#### Diabetes

In Spain, the study <u>di@bet.es</u> showed a prevalence of 12% (diagnosed and not diagnosed) among people over 18 years; interestingly, the same study detected 28.2% cases of obesity (BMI >30 kg/m<sup>2</sup>) in the whole included study population. During 2012, 10,000 people died because of complications related to diabetes (mortality rate of diabetes is 21.6 per 100,000 inhabitants).

In Catalonia, the declared prevalence of diabetes (*ESCA -Enquesta de Salut de Catalunya-*) increases with the aging of the population: it affects 7.8% of people over 15 years, 14.6% over 65 years, and reaches 26% among those over 75 years old. The estimated number of people suffering from diabetes was 560,000 in 2013.



#### Cardiovascular diseases

Generally speaking, the total number of hospitalisations during 2012 due to CVD was 13.2%. Moreover, deaths caused by CVDs were 30.3% of overall deaths in the same year.

Focusing on heart failure, its estimated prevalence in Spain is around 5%, and it reaches 10% in population up to 75 years old. It represents the first cause of hospitalisations in patients over 65 years-old (5% of overall admissions) and accounts for 2.5% of the overall Public Health Service budget. Heart failure is the third cause of death due to CVD, after ischemic cardiomyopathy and stroke. Given its usual association with other comorbidities, the estimated mortality at five years can reach 40%.

#### Stroke

In Spain, the annual incidence of stroke is 156 cases per 100,000 inhabitants, and its prevalence 500-600 cases per 100,000 inhabitants. It represents 3-4% of the global health budget (roughly  $5000 \notin$  / patient / year, excluding expenses in caregivers and social support).

According recent data from the *Departament de Salut*, 15,070 patients were admitted to Catalan hospitals due to stroke in 2014. They represent the first cause of death among women, the third among men, and the first cause of functional impairment in adults.

Similar to the successful strategies for myocardial infarct, a stroke code protocol and specific stroke units have been implemented to improve treatment, management and prognosis. The treatments of reperfusion in ischemic vascular diseases have increased from 4% to 12.5% between 2005 to 2011. A reduction of 7.1% in mortality (calculated 1,700 deaths) was achieved in Catalonia during the same period. Nevertheless, around 50% of survivors remain with some kind of disability after the acute phase of stroke.

#### Hip fractures

In Spain, there are around 3 million patients suffering from osteoporosis. The incidence of hip fracture in 2002 was 517 cases per 100,000 inhabitants / year, a bit higher in Catalonia: 658 cases per 100,000 inhabitants / year. In comparison, the Spanish population is considered with medium risk of suffering hip fractures, lower than in Northern Europe and USA, but higher than in other Mediterranean countries.

## **3.6.3** Management of the health and social problems

In order to be able to compare usual care with the new care provided by the BeyondSilos services a differentiation must be made according to the different types of users involved. This is possible by defining the care recipients involved in the short-term pathway (ICP-Short) and those involved in the long-term pathway (ICP-Long).

The generic contextualisation of the different care recipients is as follows:

- **ICP-Short:** Patients recruited after a hospitalisation, surgery, early discharge or any acute episode (including social issues). Living at home, autonomous or in a dependency situation, with home care needs or an exclusion risk due to illness or disability and living within BSA's influence area. From a social point of view, care recipients (CRs) should be frail people, socially or physically excluded due to illness or disability with home care needs. In this pathway, the patients to be included would be those that are through an acute episode.
- ICP-Long: Patients suffering heart failure or stroke plus any chronic disease, living at home, autonomous or in a dependency situation, with home care needs or an exclusion risk due to illness or disability of any condition, and living in the population within the BSA's influence area. From a clinical point of view: patients (any age) living at home, autonomous or in a dependency situation, with home care needs. We also consider as part of the BeyondSilos service pilot a second group of



users, who are the complex chronic patients. From a social point of view, CR should be fragile older people, socially or physically excluded due to illness or disability, with home care needs.

On the other hand, informal carers (family members and paid staff) are also included in the usual care when it is needed and they are available to do so. Their main role is to help older people on their daily tasks and participate in the care plan.

BSA provides a set of services according to the patient needs from both a health and social perspective. In the usual care, the interaction with the Third Sector Care (TSCP) providers is not considered because it only happens in an informal way, and it is not yet in routine service delivery. The services, from both a health and social provider perspective, are defined in Table 1.

Social care provider (SCP)	
Description of actor characteristics	<ul> <li>BSA is the provider of social services in the region of Badalona. The social workers are employed either by BSA or the City Council of Badalona.</li> <li>Besides the public body, BSA also subcontracts some of its activities to private companies to provide: <ul> <li>Home care services (family workers).</li> <li>Meals at home.</li> <li>Laundry service.</li> <li>Cleaning home.</li> <li>Tele-assistance (panic button service).</li> </ul> </li> <li>All of those external activities carried out by private providers are centrally managed by the Homecare Department.</li> </ul>
Description of role in service delivery / utilisation	They provide assistance of any type to older people that are in need of attention. Their main goal would be to provide social care and help when taking vital signs for dependent users, support for health education programmes, control and monitoring of clinical treatments, filling out forms to detect clinical alerts.
Information handled in the context of service delivery / utilisation	Coordination information. Detailed information related to the social care received / requested. Access to the whole shared care plan. Information related to the monitoring vital signs taken Internal users have full access to the EMR and SCR data set. External users (subcontracted providers) have access to some subsets of the information (demographics, shared care plan, among others) through the Homecare Department software tool.

Table 1: Provider domain actors of contextualised pathways in Badalona



Health care provider (HCP)	
Description of actor characteristics	<ul> <li>Regional public organisation provider of health services including: <ul> <li>Primary care doctors and nurses (ATDOM team) and case manager (nurse for complex chronic patients) from several sub-areas from BSA.</li> <li>Specialised care health services at Badalona's hospital.</li> <li>Badalona's hospital emergency unit staff.</li> <li>Home Care Department (SAID), home hospitalisation team.</li> <li>Home palliative care service (PADES).</li> <li>Day hospitalization</li> <li>Special tests at home</li> </ul> </li> <li>Besides the public body, BSA also subcontracts some of its activities to private companies to provide: <ul> <li>Physiotherapy at home.</li> <li>Rehabilitation at home.</li> </ul> </li> <li>All of those external activities carried by private providers are centrally managed by the Homecare Department.</li> </ul>
Description of role in service delivery / utilisation	They provide health assistance to citizens.
Information handled in the context of service delivery / utilisation	Coordination information. List of prescriptions: medication reconciliation. Full access to all the information inside the EMR and the SCR.

To give a clear overview of the foreseen improvements of interaction between actors / sectors after the new BeyondSilos service has been introduced in BSA, Table 2 shows the current interaction between sectors (usual care) and the foreseen interaction between sectors (new care) after BeyondSilos has been introduced. Any improvements from "usual care" to "new care" have been highlighted and underlined in the table. The definition of the different levels is provided in section 3.5 above.

# D6.2 Interim Evaluation Report



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Health services						
Usual care	High:	High:	Low:	High:	High:	High:
	Because of the nature of the organisation which is including the three classic healthcare levels. Clear workflows defined and ICT solutions fully integrated.	Clear workflows defined and ICT solutions fully integrated. Case Managers in every centre and any healthcare level.	Only spontaneous and informal. No formal agreements in place for the third sector to be part of the provision of care. Close relationship with the organisation because of the Health Boards.	Interaction between all the providers involved within the provision of care, either from the health or the social side. Clear workflows in place and ICT solutions greatly integrated.	Within all the healthcare levels and from a social perspective. GP as the gatekeeper to the system and the Case Manager as the one in charge of the coordination of the services provided.	Only when needed and available. Within all the healthcare levels and from a social perspective. GP as the gatekeeper to the system and the Case Manager as the one in charge of the coordination of the services provided.
New care	No changes: <u>Added value:</u> The telemonitoring tool allows the limited homecare health services to better monitor the status of the patient.	No changes	High: Only between the providers that have signed the agreement (at the moment "Amics de la gent gran" and "Fundació Roca I Pi").	No changes	No changes	No changes

Table 2: Badalona: Interactions and integration within and between sectors (comparison between usual care at start vs new care at mid-term)



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Social services						
Usual care	High:	High:	Medium:	High:	High:	High:
	Because of the nature of the organisation. Clear workflows defined and ICT solutions fully integrated. Case Managers in every centre and any healthcare level.	Because of the nature of the organisation. Clear workflows defined and ICT solutions fully integrated.	Only happening spontaneously and informally, but to a greater extent than with healthcare staff. No formal agreements in place for the third sector to be part of the provision of care. Close relationship with the organisation because of the Health Boards.	Great level of interaction between all the providers involved within the provision of care, either from the health or the social side. Clear workflows in place and ICT solutions greatly integrated.	Within all the healthcare levels and from a social perspective. GP as the gatekeeper to the system and the Case Manager as the one in charge of the coordination of the services provided.	Only when needed and available. Within all the healthcare levels and from a social perspective. GP as the gatekeeper to the system and the Case Manager as the one in charge of the coordination of the services provided.
New care	No changes	No changes	No changes	No changes	No changes	No changes



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Third sector						
Usual Care	Low: Only happening spontaneously and informally. No formal agreements in place for the third sector to be part of the provision of care. Close relationship with the organisation because of the Health Boards.	Medium: Only happening spontaneously and informally, but to a greater extent than with the healthcare staff. No formal agreements in place for the third sector to be part of the provision of care. Close relationship with the organisation because of the Health Boards.	Medium: Close relationship between them because of the Health Boards.	No interaction.	High: Only happening with the care recipients that they are able to reach outside the care provided by BSA.	High: Only when needed and available. Only happening with the care recipients that they are able to reach outside of the care provided by BSA.
New care	<b><u>High:</u></b> Only between the providers that have signed the agreement (at the moment "Amics de la gent gran" and "Fundació Roca I Pi").	High: Only between the providers that have signed the agreement (at the moment "Amics de la gent gran" and "Fundació Roca I Pi").	High: Only between the providers that have signed the agreement (at the moment "Amics de la gent gran" and "Fundació Roca I Pi").	High: Only between the providers that have signed the agreement (at the moment "Amics de la gent gran" and "Fundació Roca I Pi"). Happening through the Homecare Department software (ICR).	No changes	No changes



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Other providers						
Usual care	High: Great level of interaction between all the providers involved within the provision of care, either from the health or the social side. Clear workflows in place and ICT solutions greatly integrated (through the ICR).	High: Great level of interaction between all the providers involved within the provision of care, either from the health or the social side. Clear workflows in place and ICT solutions greatly integrated (through the ICR).	No interaction.	No interaction.	High: Coordination by the Case Manager and from an ICT perspective managed by the ICR.	High: Only when needed and available. Coordination by the Case Manager and from an ICT perspective managed by the ICR.
New care	No changes	No changes	High: Only between the providers that have signed the agreement (at the moment "Amics de la gent gran" and "Fundació Roca I Pi"). Happening through the Homecare Department software (ICR).	No changes	No changes	No changes



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage		
Person- care rec	Person- care recipient							
Usual care	High: Within all the healthcare levels and from a social perspective. GP as the gatekeeper to the system and the Case Manager as the one in charge of the coordination of the services provided.	High: Within all the healthcare levels and from a social perspective. GP as the gatekeeper to the system and the Case Manager as the one in charge of the coordination of the services provided.	High: Only happening with the care recipients that they are able to reach outside the care provided by BSA.	High: Coordination by the Case Manager and from an ICT perspective managed by the ICR.	n/a	n/a		
New care	No changes	No changes	No changes	No changes	No changes	No changes		
Family –entoura	ge							
Usual care	High: Only when needed and available. Within all the healthcare levels and from a social perspective. GP as the gatekeeper to the system and the Case Manager as the one in charge of the coordination of the services provided.	High: Only when needed and available. Within all the healthcare levels and from a social perspective. GP as the gatekeeper to the system and the Case Manager as the one in charge of the coordination of the services provided.	High: Only when needed and available. Only happening with the care recipients that they are able to reach outside of the care provided by BSA.	High: Only when needed and available. Coordination by the Case Manager and from an ICT perspective managed by the ICR.	n/a	n/a		
New care	No changes	No changes	No changes	No changes	No changes	No changes		



# **3.6.4** The ICT solution supporting integrated care (including technical characteristics of the service)

A full description of the ICT solution can be found in deliverables D3.2 BeyondSilos Service specification and D4.2 BeyondSilos Prototype system

#### Summary of the ICT solution to provide integrated care:

The following are the main elements of the ICT solution:

#### • Corporate Enterprise Resource Planner (ERP):

The organisation has a unique database and ERP (SAP) meant to manage all the administrative data. It is used by the structural services of BSA (financial, human resources, ...) and is also the central repository for patients' administrative data which is used for billing. This software is only used internally, mainly by administrative staff.

#### • Electronic Medical Record (EMR):

It is the central repository for health information about each individual patient. It is in digital format, and is capable of sharing its content amongst different care settings enterprise-wide, as well as with external care settings such as the Shared Health Record of Catalonia. The EMR is used by all administrative, health and social care staff according to access roles.

#### • Social Care Record (SCR):

It is a self-developed tool totally linked to the EMR; it is meant to store all the social information and documentation related to every individual receiving or having received social services in the city of Badalona. The SCR is mainly used by the social workers, but even healthcare staff are able to access it and check whatever social information is written there.

#### • Homecare Department Software (SAID):

It is the administrative and clinical software used to manage users that are receiving services delivered by BSA's Homecare Department. The self-developed tool is the single entry point for every patient, and also professionals (from inside and outside BSA) to provide homecare services in the city of Badalona. It also does the billing for the subcontracted services, and is accessible to the external service providers who can access some subsets of it. The users are all the stakeholders involved in the provision of integrated care. Since BeyondSilos, it includes the TSCP as part of it.

#### • Health Insight Solutions Homecare Platform (HIS):

This is the telemonitoring platform that used by BSA in the BeyondSilos project. It is a very complete solution with the following components: security sensors (including fire and water detectors, behavioural movement sensors and cell phone with GPS tracking and fall detection), comfort facilities (such as climate control, door and window locks), medical devices (including weight scale, blood pressure meter, pulseoximeter, amongst others), serious games, diary and videoconferencing system. The users of the HIS platform are the healthcare staff involved in the provision of homecare services.

A description of the technical characteristics of the application is provided in Table 3 below.



Table 3: Technical characteristics of the application

ICT building block	Technical characteristics	Development status	Level of integration	Previous experience
Corporative Enterprise Resource Planner (ERP)	The technology is a commercial product called SAP running on an Oracle database. ABAP is used as the programming language.	SAP is a robust tool, which has been used for decades in different sectors. In BSA, the implementation dates back to 2009.	It is connected to the EMRs and others through web-services provided by SAP- PI. The communication is established by HL7 messages.	This building block is the central element of the ICT systems at BSA. It has been used since 2009, and has proved its stability and reliability when holding both administrative data and providing integration with the other ICT building blocks.
Electronic Medical Record (EMR)	This is a commercial product called Gesdohc running on a PostgreSQL database. Gesdohc is written in Delphi; BSA holds the source code, so it can be modified by internal staff.	The product was implemented in 1995, making BSA one of the first paper-less centres.	The EMR is fully integrated with the ERP, the SCR, the Homecare Department software, and all the major ancillary systems (pharmacy, laboratory and X- ray).	The EMR has proved its reliability over the past 20 years dealing with all kind of patients and pathways.
Social Care Record (SCR)	The technology is a self-developed product. It is web- based, programmed in PHP, and running on a PostgreSQL database.	The SCR was developed between 2000 and 2003 after the social services of the city were entrusted to BSA. Since then, it has been continuously improved according to the specifications delivered by the social workers.	The SCR is fully integrated with the EMR and the Homecare Department software.	The SCR has been used for more than 12 years, and has proved its stability dealing with every possible situation.



ICT building block	Technical characteristics	Development status	Level of integration	Previous experience
Homecare Department Software (SAID)	This is web-based and totally linked with BSA's architecture, being able to communicate with the EMR and SCR. It is programmed in PHP and runs over a PostgreSQL database.	The Homecare Department software was developed between 2000 and 2003 after the social services of the city were entrusted to BSA. Its main aim was to give answers to the liaison between the health and the social care provision of services.	The Homecare Department sits between the EMR and the SCR. It extracts data from both of them, and enriches it with some additional information regarding the provision of care in the homecare environment. It is fully integrated within the BSA ecosystem.	After 12-15 years of use, the tool has demonstrated its capacity to deal with any kind of pathway / programme and any profile of patient.
Health Insight Solutions Homecare Platform (HIS)	It is a commercial product from HIS. It is coded in JAVA and uses a MySQL database. Management of the tool is done via a web-based portal which is written in PHP	The HIS Homecare platform is probably one of the first telemonitoring solutions. Since the first versions of the platform, improvements have been put in place following advances in technology which have further improved the care recipients' experience.	The HIS solution is fully integrated in the BSA ecosystem. The telemonitoring data is not stored at the EMR; the physicians interacting with the technology are able to access the telemonitoring information from inside the EMR in just two clicks.	An older version of the solution was already used at BSA in the context of the Home Sweet Home project, and has proved its effectiveness.

## 3.6.5 Requirements for use of the ICT solution

Regarding the requirements on the use of the ICT systems already in place, one must distinguish between the types of stakeholder interacting with it:

- **Professional staff (including HCP, SCP and TSCP):** As most of the solutions are web-based, these types of professionals only need a web browser to interact with all the different ICT building blocks. For them to learn about the solution, training is provided and delivered by a key-user who is better able to explain the use of such a tool from both the technical and the functional perspective.
- **Care recipient and informal staff:** Both types of users only interact with the telemonitoring solution. The hardware (tablet / PC with Internet connection and medical devices) and the software to be used are provided by BSA. Training of one hour is delivered to both stakeholders by a technical person from the R&D&I Department (use of the application) and the Case Manager who is responsible of the patient (care plan).



## **3.6.6 Case description**

#### **3.6.6.1** Case description for ICP-Short

- Included roles: Care recipient (CR), Health care staff (HCP), Social care staff (SCP), Third sector care provider (TSCP) and Informal Caregiver (I/FC).
- ICT building blocks: Electronic Medical Record (EMR), Social Care Record (SCR), Homecare Department Software (ICR) and HIS Telemonitoring solution (HIS).
- Main objective: Rehabilitation and back to independent life.

Maria (CR), 73 years old. Maria is an active hard working widow. She is retired and lives alone in Badalona since her husband died three years ago. She has a daughter (I/FC), who lives in the city but in another neighbourhood. Her daughter worries about the safety of her mum after her father's death, and managed to convince her to get the panic button functionality enabled. It was a long fight with Maria, because she felt safe on her own. In the end, between her daughter and the social worker (SCP) assigned to her, they managed to start with the service.

Regarding her health conditions, Maria is overweight, with a BMI of 27. During a visit to the GP (HCP) that took place two years ago, high blood pressure was diagnosed. Maria was advised to carefully watch her food intake and to take medication on a daily basis. This is not a problem for Maria: she takes her medication consistently and tries to adapt her diet to the recommendations provided by her GP (HCP).

Maria recently had a fall while she was leaving the bathtub. Luckily for her she was wearing the panic button and could press it. The specialised Contact Centre, which takes care of the panic button functionality, called her but they did not receive any answer. After not receiving an answer, they called the daughter and went to the house after picking up a copy of the keys up at the Badalona's Hospital (HCP) which they have in custody. Only authorised personnel are able to access the cupboard were these keys are held, and a strong registration and control process is put on the top of that through a module attached to the Homecare Department Software.

When the emergency team (HCP) arrived at the house, they discovered Maria lying in the bathroom. They brought her to the Hospital (HCP) where a hip fracture was diagnosed, which led into urgent surgery. What a bad situation!

Fortunately for Maria, this happened to her in Badalona, a city were patient needs are at the centre of the provision of care.

Right after the surgery, the surgeon that took care of her at the Hospital was able to request that Maria be included in the Early Discharge programme directly through the EMR. The day after of the surgery, the Case Manager (HCP/SCP) who is working at the Hospital approached Maria and her daughter, and was able to perform an integral assessment of Maria's specific needs with the end objective of rehabilitating Maria. The assessment defined a shock intervention plan lasting for six weeks, starting two days after the surgery once Maria was discharged back home, and consisted of enabling the following services:

- Home Hospitalisation (HCP): to follow up on the wounds resulting from the surgery.
- Physiotherapy team (HCP): to gain back the lost mobility.
- Family worker at home (SCP): to help Maria with daily tasks and to help her daughter who is not able to fully attend.
- Meals at home (SCP): to ensure that Maria is able to follow her diet.
- HIS telemonitoring solution (HCP): to better control Maria and receive questionnaires from her.
- Panic button functionality and key custody (SCP): Maria is already in the programme and no further action is needed.
- Home Fixings and arrangements (TSCP): to make an assessment about the possibility of changing the bathtub for a shower. According to Maria's economic possibilities "Fundació Roca I Pi" would pay for the exchange.



The Case Manager goes into the EMR and the SCR and registers all the information. The information is fully accessible by all the health and social staff working in Badalona according to access roles. Further to that, the Case Manager designs the integrated common care pathway for homecare support which includes all the services above within the ICR. In there, she specifies clearly the teams that will provide the service, the days the interventions are going to be done, and everything related to Maria which should be needed by those teams. Those teams are able to access the shared care plan and know about all the interventions done for Maria, even some by third party organisations. Finally, the Case Manager delivers the shared care plan to Maria and her daughter, and arranges for a visit to provide the short training about the use of the telemonitoring tool.

The visits performed by the different teams will be registered in the ICR, which is accessible by all the social and health staff within the city. Further to that, the specific health and social care information will go to the EMR and the SCR respectively. The telemonitoring solution is also accessible by all the healthcare professionals involved within the provision of care, ranging from the GP to the specialist.

#### 3.6.6.2 Case description for ICP-Long

- Included roles: Care recipient (CR), Health care staff (HCP), Social care staff (SCP), Third sector care provider (TSCP) and Informal Caregiver (I/FC).
- ICT building blocks: Electronic Medical Record (EMR), Social Care Record (SCR), Homecare Department Software (ICR) and HIS Telemonitoring solution (HIS).
- Main objective: Better control chronic conditions and avoid institutionalisation.

Jordi (CR), 69 years old. He is a married, social person and slightly overweight. He and his wife Georgina live together in Badalona. He used to spend a lot of time in a local bar. He was a truck driver, a job that included irregular work hours. For a while now he has been retired. He never took care of his health and drank and smoked a lot.

Back in the days when he was 51, he was diagnosed with diabetes by the endocrinologist (HCP). Now, four years after his retirement and after a referral by the GP (HCP) to the cardiologist (HCP), heart failure was diagnosed due to an old myocardial infarction, something Jordi did not expect. His diagnosis also revealed he had symptoms of fluid overload. Now Jordi takes medication, and is advised to lose weight and adopt a healthy lifestyle. He has to carefully regulate his fluid (maximum 1500 cc) and sodium (maximum 2 gr) intake to prevent excess fluid from accumulating in his lungs and in his legs or abdomen. Controlling his drinking is difficult, since he is always so thirsty; cooking has become a hassle for his wife who struggles with the new diet. Jordi suffers from his condition every day, and is not able to enjoy his retirement going out with his friends. Heart failure has great impact on his daily functioning since he cannot seem to adopt the desired behaviour.

Things could not turn worse when her wife died. Jordi was more or less maintaining his diet thanks to his wife, but now that he is also learning to cook, adapting himself to a healthy diet is difficult. Jordi often eats out, and when he tries to prepare healthy meals he relies on processed ingredients due to his limited cooking skills. He is never sure what ingredients are used in processed food or restaurants, but he just enjoys them more. Besides, Jordi feels that the medication will improve his blood pressure (he also is hypertensive) so much that he can keep enjoying this kind of food. Without an intervention, Jordi continues his lifestyle and his blood pressure becomes worse without any clear symptoms.

This situation has brought Jordi into closing himself at home. He has totally left his friends and closed in on himself to cry for his loss and bad health conditions. He is under late life depression.

Fortunately for Jordi, such a bad situation is happening to him in Badalona, a city were patient needs are at the centre of the provision of care. That is why after missing a couple of visits, Jordi's GP decides to take action and alerts the reference Case Manager (HCP/SCP) for that Primary Care Centre.


The Case Manager is able to find Jordi just calling by phone, and decides to visit him. In there, she clearly identifies the situation and comes up with a specific plan tailored to Jordi's needs. Coming from the assessment done by the Case Manager, she decides to enable in the ICR the following services:

- ATDOM Service (HCP): to regularly check on Jordi's status (a programme meant for those CRs who are not attending the Primary Care Centres for any reason).
- Telemonitoring solution (HCP): to better control Jordi's health-related conditions and to change his behaviour through training material delivered by the platform.
- Family worker (SCP): to show him how to cook healthily.
- "Amics de la gent gran" (TSCP): to enable volunteers who fight against social exclusion and social isolation (and can help to fight late life depression).

The process afterwards remains the same as in the previous case.

# 3.7 Domain 1: Valencia

## **3.7.1** Description of the health and social problem

In Valencia pilot site we include complex chronic patients from Case Management Care Programme (CMCP) deployed in Valencia-La Fe Health Department. Among the 700 patients enrolled in this programme, we find several diseases; for those who are included in BeyondSilos study we have patients who cover all diseases aimed at in BeyondSilos: COPD, CVDs and diabetes. However, the majority of the care recipients included in the BeyondSilos project will have CVDs as the main diagnosis.

The population that we attend in our environment (Valencia-La Fe Health Department) are retired men or women (mostly pensioners) who have a median of 72 years, with more than one chronic disease, and need some kind of help to develop their daily tasks. They are a population that risks suffering a decompensation; due to that, they are part of the CMCP. They usually have relatives (sons and daughters), but live alone or as a couple. They often have the company of an informal career (usually non-professional) when they are a widow or widower, or when they are frail and relatives are not responsible for them.

At the social level, we do not detect severe social problems among our target population. The most common social determinant in our environment is social isolation because their chronic conditions do not permit them to have social interactions. They should ask for social support to avoid this isolation. Coordination between social care providers and healthcare providers is weak. For patients included in CMCP, prior social needs are evaluated, but not attended directly; social workers belonging to Valencia La Fe Health Department advise patients on the different options of social aid offered by regional government, or if detecting social alert in a specific case, they deliver this case to Social and Welfare Regional Ministry or social area of city administration to evaluate the case.

#### 3.7.2 Quantification of the burden of disease / health problem and social problem

#### Cardiovascular diseases

In Spain, deaths caused by CVDs were 30,3% of overall deaths in year 2012. 13,2% of hospitalisations during 2012 were due to CVDs.

#### Chronic Obstructive Pulmonary Disease (COPD)

In our territory (Spain), the prevalence of COPD is around 10% for patients between 40 and 80 years old. Deaths caused by COPD are 18,000 per year, which means this is the fifth death cause for men in Spain and seventh cause of death among women.



#### Diabetes

In Spain, latest studies shows a prevalence of 14% of diabetes (diagnosed and non-diagnosed) among people over 18 years. During 2012, 10,000 people died because of complications related with diabetes. Rate of mortality of diabetes is 21.6 per 100,000 inhabitants.

Among those that we have in our target group (200 complex chronic CMCP patients), we identified 126 with CVDs that represent 63% of our target group. Among the remaining potential users, 47 were identify with COPD (23.5%) and 27 with diabetes (13.5%). Among those 200 patients identified, around 10% could have social need related to their disease; some others could also express some social issues during first contact, but this does not mean that they have real social needs, but only a perception of need. During enrolment of patients, we could be more accurate with these social needs. Epidemiological study of cardiovascular diseases in Valencia region conducted by Public Health Department of Regional Government shows that in 2012 Valencia Region has a rate of 32.2% of deaths related to CVDs. Gender analysis shows that women have a higher rate (34.5%) than men (28.3%).



Mortality distribution for each disease in Valencia is represented Figure 2 below.

Figure 2: Mortality distribution for diseases in Valencia

Main risk factors associated with CVDs in Valencia region are: obesity, sedentary lifestyle, diabetes mellitus, hypertension and smoking.

CVDs have high mortality and morbidity with significant deterioration in the quality of life, frequent hospitalisations (main reason for medical admission), with significant resource consumption. CVDs account for 1-2% of the overall health cost, of which 75% it is attributable to hospitalisations, and an occupation of 10% of hospital beds.

According to the national survey of hospital morbidity in the Region of Valencia, hospital discharges for CVDs are approximately 220 per 100,000 habitants, creating in 2009 a total of 76,022 admissions with an average length of stay of 7.42 days.

In our region, COPD causes 10-12% of consultations in primary care, 35-40% of the pneumology consultations, and 7% of hospital admissions. In 2009, hospital discharges for COPD were 182 per 100,000 inhabitants in the Valencia Region, with a total of 72,883 stays and an average of hospital stay of 6.62 days. Gross death rate in Valencia is 33.3 deaths per 100,000 inhabitants, making it the sixth leading cause of death.



Prevalence of diabetes in Valencia region is near 13%, according to numbers presented by Plan of Diabetes. Gross death rate for diabetes in Valencia is 26.2 per 100,000 inhabitants.

The average cost of people with type 2 diabetes treated in primary care, estimated in the CODE-2 study (2002), was  $1,305 \notin$  / year (42% pharmacy, 32% hospitalisation, and 26% healthcare). In Valencia, the aggregate expenditure in diabetes in 2005, not taking into account technology, laboratory, radiology and other test costs, has been around 88 million  $\notin$  (44.9% drugs, 27.8% reactive strips, 15.8% healthcare workers, 11.1% for hospitalisation)

#### **3.7.3** Management of the health and social problems

Valencia-La Fe Health Department, aligned with Agencia Valenciana de Salud, drives innovation strategies for chronic patients, introducing a proactive care model which aims for better control of patients while they are at home; the main objective is to obtain long stability periods, to reduce the number of decompensations, improve symptoms control, and increase quality of life perception; as a consequence of all of this, a decreased use of resources due to instability periods.

The case management model includes the common elements of case management: client identification and selection, assessment and problem identification, development of the case management plan (including coordination of care activities) and evaluation of the case management plan. All these elements have been adapted by Health Department of La Fe reorganising and integrating resources of specialised and primary care.

Valencia-La Fe Health Department has developed a predictive model which is based on analysis of chronic pathologies (such as COPD, diabetes or CVDs) and previous resource consumption; it permits identifying patients who would benefit from case management programme.

The Kaiser Permanent Model (combined predictive model of health dialogue, King's Fund and New York University) has been taken into consideration to identify the target population and allocate to the pertinent care complexity level.

- Level 3. Case Management. Includes population with one or more chronic diseases which may require a more intensive level of care, often referred to as 'case / care management', a co-ordinated and proactive approach to improve health and help them to avoid being admitted to hospital unnecessarily.
- Level 2. Disease Management. Includes population with one or more chronic diseases which may need a greater level of professional support to help avoid complications or slow the progression of disease.
- Level 1. Self-care. Population with one or more chronic diseases who are given the information and other practical support they require to manage their own conditions in a way that helps them use this information to their own benefit.
- Level 0. Health promotion and prevention. Population-wide prevention, health promotion and targeted health improvement activity, through action to prevent disease, raise awareness of risks to health and support healthy lifestyle choices.





Figure 3: Valencia care complexity levels

The population stratification depends on the severity level of the chronic condition (COPD, CVDs and diabetes) and the risk of further non-scheduled care that patients may need identified by the predictive model.

Taking advantage of the introduction of new technologies, aimed to ensure continuity of information and availability for all actors involved, the potential patient candidates for CMCP are labelled in hospital and primary health care clinical history, using a traffic light system. The clinical team in charge of each patient identified should check the inclusion criteria; if suitable, they should programme the patient for assessment and case management enrolment.

The patient evaluation should include a complete health and psychosocial assessment using standardised tools depending on target disease (COPD, diabetes or CVDs). Before hospital discharge to CMCP, a social evaluation is conducted to detect social needs and assess patients where they ask for social aid. Social workers belonging to Valencia La Fe Health Department advise patients of the different options of social aid offered by regional government, or if they detect a social alert for a specific case, they deliver this case to Social and Welfare Regional Ministry or social area of city administration to evaluate the case.

Together with the assessment, educational and preventive interventions related specifically to the chronic diseases of the patient (COPD, CVD or diabetes) are developed (known as Educational and Secondary Prevention Programme, the Spanish acronym is PEPS).

The clinical team for the initial assessment (recruitment) in primary healthcare is composed of: GP, nurse, and community case manager nurse. The clinical team for recruitment in the hospital setting belongs to Hospital at Home Unit where patients will be identified as candidates.

The care plan for complex chronic patients is based on primary health scheduled intervention and demand attention response (home visits and/or consultations by GP, nurse and community case manager nurse).

Besides the primary healthcare team which is the key actor for chronic patients care management, the health department has the support of the Hospital at Home and Telemedicine Unit. This Unit is led by hospital case manager nurses responsible for the remote follow-up (phone calls) of chronic complex patients to assure the needs of patients and their relatives.





Figure 4: Valencia chronic disease management process

In short, a patient with complex chronic diseases (patients hospitalised, detected by predictive model, or enrolled by primary care) who is included in CMCP will have an agreed care plan among the different actors involved, then a scheduled inclusion visit on the part of Hospital at Home during which a prevention education intervention is launched (for the following three days) where patients will be educated in empowerment for his disease. Once this programme ends, a plan of scheduled visits and phone calls will be establish, depending on patients' needs, and followed up by his referent Case Management Nurse in Hospital La Fe Telemedicine Unit.

If a patient is included in CMCP after a hospital discharge, a previous emergency or descompensation, a psychosocial evaluation is conducted in order to detect social needs.

To give a clear overview of the foreseen improvements of interaction between actors/sectors after the new BeyondSilos service has been introduced in Valencia, Table 4 shows the current interaction between sectors (usual care) and the foreseen interaction between sectors (new care) after BeyondSilos has been introduced. Any improvements from "usual care" to "new care" have been highlighted and underlined in the table. The definition of the different levels is provided in section 3.5 above.



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Health services	·			·		•
Usual care at start	High: Case Management Care Plan (CMCP) is running as a service of Valencia-La Fe Health Department portfolio.	None: There are no social services in routine use for caring for CMCP users.	None: No interaction between health care services and third sector.	Low: Only when the care recipient hires these services or pays for them with a grant from the Municipality.	High: Case management care through telehealth.	Medium: Support for patient management through telehealth.
New care at midterm	Added value: Improvement of CMCP with ICT tools for patient self-management.	High: A new social provider who takes care of patients for evaluation and follow-up in social care.	Unchanged: Still no interaction between these stakeholders.	Unchanged: Only when the care recipient hires these services or pays for them with a grant from the Municipality	Added Value : Self-management through telehealth + ICT tools.	High: Accurate follow up / control of care recipients through eHealth assistance.
Usual care at start	None: There are no social services in routine use for caring for CMCP users.	High: Social services could be provided by regional government in some cases, and hired as a private company in others.	Low: Only when the care recipient hires these services or receives a grant from the Municipality.	Low: Only when the care recipient hires these services or pays for them with a grant from the Municipality.	Medium: Only when persons have been assigned or hired for these services.	Medium: Only when patients have been assigned or hired for these services.
New care at midterm	High: A new social provider who takes care of patients for evaluation and follow-up in social care.	Added Value: Coordination with health services to improve patients' care.	Unchanged: Interaction still spontaneous.	Unchanged: Interaction still spontaneous.	High: Tele-assistance social follow up for all care recipients.	High: Accurate follow up / control of care recipients through telecare assistance.

Table 4: Valencia: Interactions and integration within and between sectors (comparison between usual care at start vs new care at mid-term)



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Third sector						
Usual care at	None:	Low:	Low:	Low:	Low:	Low:
start	No interaction between	Only when the care	Could happen	Could happen	Only happening	Only happening
	healthcare services and	recipients hire these	spontaneously when	spontaneously when	spontaneously and	spontaneously and
	third sector.	services or receive a	patient acquires	patient acquires these	informally. No formal	informally. No formal
		grant from the	these services.	services.	agreements in place for	agreements in place
		Municipality.			the third sector to be	for the third sector to
					part of the provision of	be part of the
					care.	provision of care.
New care at	Unchanged <u>:</u>	Unchanged:	Unchanged:	Unchanged:	Unchanged:	Unchanged:
midterm	Still no interactions	Still low interaction,	Still low interaction,	Still low interaction,	Still low interaction,	Still low interaction,
	between stakeholders.	only spontaneously.	only spontaneously.	only spontaneously.	only spontaneously.	only spontaneously.
Other providers		•	•		•	
Usual care at	Low:	Low:	Low:	Low:	Low:	Low:
start	Could happen	Only happening	Could happen	Could happen	Only happening	Only happening
	spontaneously when	spontaneously and	spontaneously when	spontaneously when	spontaneously and	spontaneously and
	patient acquires these	informally. No formal	patient acquires	patient acquires these	informally. No formal	informally. No formal
	services.	agreements in place.	these services.	services.	agreements in place for	agreements in place
					the third sector to be	for the third sector to
					part of the provision of	be part of the
					care.	provision of care.
New care at	Unchanged:	Unchanged:	Unchanged:	Unchanged:	No Changes:	No Changes:
midterm	Still low interaction, only	Still low interaction,	Still low interaction,	Still low interaction,	Added value: when	Added value: when
	spontaneously.	only spontaneously.	only spontaneously.	only spontaneously.	hired, the services	hired, the services
					delivered are	delivered are
					integrated in Patient	integrated in Patient
					Management Plan.	Management Plan.



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage		
Person- care reci	Person- care recipient							
Usual care at start	High: Patients are users of Case Management Care Plan through telehealth.	Medium: Only when persons have been assigned or hired these services.	Low: Only happening spontaneously and informally. No formal agreements in place for the third sector to be part of the provision of care.	Low: Only happening spontaneously and informally. No formal agreements in place.	N/A	N/A.		
New care at midterm	Added Value : Self-management through telehealth + ICT tools.	High: Tele-assistance social follow up for all care recipients.	Unchanged: Still low interaction, only spontaneously.	Unchanged: Still low interaction, only spontaneously.	N/A	N/A		
Family –entoura	ge							
Usual care at start	Medium: Support for patient management through telehealth.	Medium: Only when persons have been assigned or hired these services	Low: Only happening spontaneously and informally.	Low: Only happening spontaneously and informally.	N/A	N/A		
New care at midterm	High: Accurate follow up / control of care recipients through eHealth assistance	High: Improved service with social care tele- assistance.	Unchanged: Still low interaction, only spontaneously.	Unchanged: Still low interaction, only spontaneously.	N/A	N/A		



# **3.7.4** The ICT solution supporting integrated care (including technical characteristics of the service)

A full description of the ICT solution can be found in deliverables D3.2 BeyondSilos Service specification and D4.2 BeyondSilos Prototype system. In summary:

In order to achieve BeyondSilos purposes, an existing multiplatform technological tool (Nomhad Chronic<sup>®</sup>) in our Health Department will be adapted. This platform allows regular follow-up of patients through different devices, and analysing information received; it could offer specific personalised information about their disease (COPD, diabetes and CVDs) to patients and caregivers.

Social information is being integrated with the platform during BeyondSilos project. That is going to be a great improvement in terms of patients care integration, because medical staff could have key social information from patients and vice versa. Medical problems such as CVDs, COPD, and diabetes have social consequences beyond the health ones; integrating information from both spheres will mean an increase in patients' quality of life and quality of attention.

La Fe has a complex process for providing integrated care to those patients that are part of the Case Management programme. In BeyondSilos, this complex process has been complemented with the collaboration of a social provider Atenzia.

The main role played by the technology is focused on the use of systems for the self-care and self-control by patient and relatives, now including the social perspective, and the technology used by the social provider in order to keep the person safe and independent at home. The information gathered by the social provider is now shared with the Case Management programme at the hospital, and vice versa, providing a whole and integrated view of the person social-care dimension.

Health Department Valencia-La Fe Pilot site had three components already working at the beginning of the project; these components are Abucasis, Orion Clinic and NOMHAD. This corresponds with the "old IT" to be integrated with the following new developments: predictive modelling building block; and the integration of the social dimension in the care process of La Fe.

NOMHAD is the ICT component in charge of the general telemonitoring building block; its development status is on-going. Before BeyondSilos, NOMHAD had implemented health monitoring, but it has no monitoring for social purposes, so social care monitoring is being implemented to add the social perspective to the current patient management in order to implement Integrated Care. It allows measurement monitoring (weight scale, blood pressure meter, pulseoximeter, amongst others), questionnaires, education contents and empowerment tools, diaries, appointments, medication, etc.

## **3.7.5** Requirements for use of the ICT solution

In order to receive self-management patient data, we provide participants with PC tablet with Android system, and adapted by TSB for BeyondSilos. Those PC tablets have Bluetooth application to connect with medical devices (blood pressure device and pulseoximeter device), and we also provide a SIM card in order to allow patients to send their data.

No specific training related to the ICT platform will be conducted for Telemedicine Unit staff, because they are already familiar with the platform from previous experiences. If booster training is be needed, this will be conducted by BeyondSilos Management Team.

For social providers (Atenzia), shared information about care recipients involving ICT platform may need some training; this will be conducted by BeyondSilos Management Team.



For the rest of health staff involved in the new care model from BeyondSilos, they do not have to enter any data through ICT platform, so they do not need specific training.

Training courses on the use of the biomedical devices, PC tablet device and remote home teleassistance devices will be provided to care recipients and their relatives. This training will be provided by healthcare professionals from Hospital at Home unit, and conducted in patient's home. Any doubt that could arise after the training will bere solved by BeyondSilos Management Team Training.

## 3.7.6 Case description

Mr. Perez, male 78 years old, is diagnosed with heart failure and secondary diabetes. He is a pensioner (he has been worked in accounting in a national company) and lives with his wife. Mrs. Perez underwent surgery last year to place a prosthesis on her knee, so she has reduced mobility. Their sons have hired a non-professional career who helps Mr & Mrs Perez with their daily activities. Mr. Perez was identified through our predictive model (through his symptoms and previous visits to hospital) as a patient with high risk of suffering a decompensation, so he was included in the Health's Department CMCP, where he stayed for almost three years. Mr. Perez has a long period of stability in his disease, and is considered as a well-controlled patient.

He has been invited to participate in the BeyondSilos study through a phone call from Case Management Nurse, who has good relationship and confidence with him and his wife.

Mr Perez agreed to participate and a nurse (member of BeyondSilos project team in Hospital la Fe) schedules a home visit to explain the study to him and to obtain Inform Consent Form in order to begin training process. A complete explanation about how PC tablet and devices linked with it works and the new care pathway is explained to Mr. Perez and his informal caregiver. Nurse helps him and his caregiver to send first measurements, to make them more comfortable with all the technical devices that they will keep at home.

During the first week Mr. Perez is asked to send measurements in order to check that everything works. When technical problems appeared during first measurements, Mr. Perez called and BeyondSilos technological provider (TSB) went to Mr. Perez home to solve the problem, but they could not, so finally substituted Mr. Perez device. He and his caregiver continue to send their measurements correctly. During this first week, social provider (Atenzia) agreed with Mr. Perez a visit to install their telemedicine device and to solve any doubts related to the study that he, his wife, or his caregiver might have.

Once Mr. Perez has everything in place, regular contacts (previously schedule depending on Mr. Perez's needs) take place from Case Management Nurses for clinical issues and Atenzia social workers for social issues. Mr. Perez has the possibility to contact his CMN for any question related to health, and Atenzia for any social questions, whenever he wants, and also for technical issues, which Atenzia forwards to TSB to solve the problem.

If any of measurements and questionnaires send by Mr. Perez, as well as phone calls, lead nurses or social workers to understand that something is going wrong with Mr. Perez, establish protocols will be initiated. For a clinical issue, CMN will contact Mr. Perez to evaluate if a Home Care Unit or primary care unit have to visit him to evaluate the situation and take a decision. If it is social issue, Atenzia will evaluate the case, and if it is necessary schedule a visit to Mr. Perez's home; once in his home, if the emergency is related to social problem, they activate the usual circuits with welfare Regional government; if it also includes some clinical issues, they will call emergency services.

After four months of follow up, Mr. Perez will receive Atenzia social workers visits to check that everything related to Mr. Perez's environment is OK, or maybe needs some intervention. After eight month of follow up, BeyondSilos team will visit Mr. Perez to close follow up and collect final questionnaires.



## 3.8 Domain 1: Campania

#### 3.8.1 Description of the health and social problem

In Campania we will include care recipients of the Local Health Authorities service of integrated care, also called ADI (Assistenza Domiciliare Integrata, – integrated home care), who are usually persons / patients with a very low level of independence, since they are often unable to attend to their daily life. Within this category of patients, we have chosen those that suffer from heart failure, as defined by the American Heart Association classification (severity of heart failure ranging from class A to class D). Given the high level of dependency, these patients represent an important burden to their families, which is in part mitigated by ADI programmes. These provide health and social care support to the family, through visits from nurses, physicians and also operators of social services, trained for person care. For a general description of the diseases and social situation, please see sections 3.3 and 3.4. The care recipients included in BeyondSilos will all have been diagnosed with at least one of the following ICD-9 codes:

- 428.0 Congestive heart failure unspecified.
- 428.1 Left heart failure.
- 428.20 Unspecified systolic heart failure.
- 428.21 Acute systolic heart failure.
- 428.22 Chronic systolic heart failure.
- 428.23 Acute or chronic systolic heart failure.
- 428.30 Unspecified diastolic heart failure.
- 428.31 Acute diastolic heart failure.
- 428.32 Chronic diastolic heart failure.
- 428.33 Acute or chronic diastolic heart failure.
- 428.40 Unspecified combined systolic and diastolic heart failure.
- 428.41 Acute combined systolic and diastolic heart failure.
- 428.42 Chronic combined systolic and diastolic heart failure.
- 428.43 Acute or chronic combined systolic and diastolic heart failure.
- 428.9 Heart failure unspecified.

#### 3.8.2 Quantification of the burden of disease / health problem and social problem

In Campania, in 2003, about 300 per 100,000 citizens were admitted to hospital with a diagnosis within the ICD-9 of 428-x. The trends were towards an annual 1% increase; therefore we can estimate that in 2013, about 330 patients out of 100,000 patients are affected by the condition. Campania population is 6,000,000 people in 2015, with an estimate of 19,500 patients affected by the disease that are admitted to hospital. Of them, an estimate of 25% will also have social problem, based on demographics and age over 65 years. Given that these patients are not able to go out easily, they need continuous attendance from their relatives, who in turn cannot lead a regular social life. Health and social care allows the family to get some relief, and to attend to their daily life for some hours. Often, these patients are assisted by paid informal caregivers (so called "Badanti", personal private assistants) that allow for personal support. It is esteemed that about 22% of patients at home are attended by a paid informal caregiver. Continuity of care is often not offered by the ADI service, and in case of emergency, patients often refer to the emergency department of the Local Health Authorities (so called 118 number) or to hospitals.



#### 3.8.3 Management of the health and social problems

The Campania pilot in Salerno and Napoli is based on the existing ADI infrastructures in the territory: ADI service is provided to older patients in need of assistance at home due to health problems and the lack of independence. The ADI is organized in Campania as a common effort between social services belonging to the Municipality and the Regional public healthcare system. The level of digitalisation of such services is very low, and there is a lack of online communication between the two administrations providing the service. Furthermore, there is no home monitoring service for clinical parameters available. The family is often significantly involved in the management of patients; despite the presence of ADI, their role is still predominant in the delivery of care to patients. BeyondSilos adds to the current management of patients a closer monitoring of the heart failure progression. First of all, the digitalisation of management is provided, in collaboration with Magaldi Life (a private company specialised in the field), by the creation of a platform where the data of the patients, both administrative and clinical, converge. This platform allows for the continuous monitoring of what is delivered at the patient place, with particular focus on the number of accesses, the intensity of the care, and the costs that are related to the service. Also, by means of telemedicine, the service allows for the monitoring of cardiovascular parameters such as blood pressure and heart rate, and body weight (expression of fluid retention typical of heart failure) and peripheral blood saturation (expression of poor pulmonary circulation function, and therefore anticipatory of cardiac decompensation). We also monitor blood glucose in diabetics, which is linked to the evolution of chronic heart failure.

Patients that are enrolled with the ADI programme are usually defined as not sufficient, and assessed by a multiple dimension evaluation team. Once the team identifies the needs of a patient, it prepares an integrated care pathway that includes nurses, social workers, physicians and territorial geriatricians. With the pathway, the team can also decide to include BeyondSilos assessment and home monitoring. Patients also have access to the University Hospital for a specialist clinical assessment from cardiologist, rheumatologist, neurologist and anaesthesiologist of the University of Salerno. At the home of the patient, nurses and social workers deliver care and track their activity on the electronic record of the patient. In addition, patients, and relatives of non independent patients acting as informal caregivers, can feed the records using the home deployed devices.

To give a clear overview of the foreseen improvements of interaction between actors / sectors after the new BeyondSilos service has been introduced in Campania, Table 5 shows the current interaction between sectors (usual care) and the foreseen interaction between sectors (new care) after BeyondSilos has been introduced. Any improvements from "usual care" to "new care" have been highlighted and underlined in the table. The definition of the different levels is provided in section 3.5 above.



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Health service	S					
Usual care	Low: GP and specialists relate occasionally.	Medium: Common evaluation; independent delivery of care.	Not Included in ADI	Not Included in ADI	Medium: Case management.	Medium: Support for patient management.
New care	<u>Medium:</u> GP and specialists share document.	High: Common evaluation; coordinated delivery of care.	Not Included in ADI	Not Included in ADI	High: Case management; self assessment by ICT tools.	High: Support for patient management through telemedicine + ICT tools.
Social services						
Usual care	Medium: Common evaluation; independent delivery of care.		Not Included in ADI	Not Included in ADI	Low: Patients receive assistance according to integrated plan.	Low: Support for relatives in assisting patients.
New care	High: Common evaluation; coordinated delivery of care.		Not Included in ADI	Not Included in ADI	<u>Medium:</u> Patients receive assistance according to integrated plan + ICT.	<u>Medium:</u> Support for relatives in assisting patients.
Third sector	·	·	·	·	·	·
Usual Care	Non included in ADI	Non included in ADI	Non included in ADI	Non included in ADI	Non included in ADI	Non included in ADI
New care	No changes	No changes	No changes	No changes	No changes	No changes

Table 5: Campania: Interactions and integration within and between sectors (comparison between usual care at start vs new care at mid-term)



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Other provide	rs					
Usual care	Non included in ADI	Non included in ADI	Non included in ADI	Non included in ADI	Non included in ADI	Non included in ADI
New care	No changes	No changes	No changes	No changes	No changes	No changes
Person- care re	ecipient					
Usual care	Medium: Case management.	Low: Patients receive assistance according to integrated plan.	Not Included in ADI	Not Included in ADI		Medium: Participation in patient disease management.
New care	High: Case management; self assessment by ICT tools.	Medium: Patients receive assistance according to integrated plan + ICT.	Not Included in ADI	Not Included in ADI		High: Participation in patient disease management using home devices.
Family –entou	rage					
Usual care	Medium: Support for patient management.	Low: Support for relatives in assisting patients.	Not Included in ADI	Not Included in ADI	Medium: Participation in patient disease management.	
New care	High: Support for patient management through telemedicine + ICT tools.	Medium: Support for relatives in assisting patients.	Not Included in ADI	Not Included in ADI	<u>High:</u> Participation in patient disease management using home devices.	



# **3.8.4** The ICT solution supporting integrated care (including technical characteristics of the service)

A full description of the ICT solution can be found in deliverables D3.2 BeyondSilos Service specification and D4.2 BeyondSilos Prototype system.

Within BeyondSilos, we aim to close the gap between health and social care. In particular, the digital infrastructure will be used to support formalised cooperation, by joint access to an extended electronic care record (eCR).

BeyondSilos will enable home monitoring of clinically relevant parameters that will be stored in the eCR. During the pilot, service users will have remote access to the personal electronic file.

Participants in the intervention group receive the "new" integrated home care. This new care will benefit from ICT facilities / devices. Homes will be equipped with health monitoring devices. Medical personal devices will consist of:

- Wireless blood pressure and heart rate sensor.
- Wireless weight scale.
- Wireless glucometer.
- Wireless pulse oximeter.

Measurements of physiological parameters through means of the wireless devices are taken on a regular basis once a week. In order to make the protocol the least intrusive, participants are free to choose the time of their daily measurements.

The technology used for collecting and transmitting data is commercially available, while the ICT solution for integrating data received from home devices into the patient database has been tailored on the available database.

The use of a telematics follow-up for patients with chronic cardiovascular diseases such as hypertension and heart failure has been established in Salerno four years ago. The system allows for sharing patient health record over the web, between the hospital and GPs. It has never been implemented with home deployed devices, although GPs can input patients' data through web access.

## 3.8.5 Requirements for use of the ICT solution

The service is implemented on an ICT platform that is used for the management of patients that have access to the ADI, the integrated Home Care. The servers of the ICT are hosted within the Local Health Authority of Salerno. Through G3 connections, tablets and devices are able to transmit patients' data to the database, where they are safely stored according to identifying codes associated with the patient. The described devices are used to monitor parameters that can monitor evolution of the cardiovascular disease, including water retention, metabolic alterations, and dyspnea. Patients and caregivers receive a brief introduction to the devices and to the system. Personnel are trained in the delivery of evaluation questionnaires.

#### 3.8.6 Case description

Pasquale is a 74 year old retired doorman, hypertensive, overweight, smokes of a pack of cigarettes a day ("but I do not inhale"), who for the last five years has attended his wife affected by an incapacitating chronic disease that has forced her to bed. He has spent a lot of time and money taking care of her, but he did not take care of his own life style appropriately, and now that his wife is dead, he has even less interest in life. He lives alone, and occasionally his daughter Anna comes to see him. She is a working



woman, married with kids, and living far from her father, so she cannot visit him very often. When she called last time, he did not answer the phone, and that scared and convinced her for an extra visit. When she found the father lying unconscious, she called the emergency number. The father was taken to the nearest hospital, where he was diagnosed an MI complicated by arrhythmia and stroke. After hospital discharge, the father, following cardiac failure and a stroke, was no longer able to live alone, and therefore the daughter took him to live with her. Since Pasquale cannot get out of bed without help, the family of the daughter is burdened with a huge load of work, and they organised turns to attend Pasquale in bed. The family doctor activates the ADI, a programme of integrated care that is paid for by the Local Health Authority (ASL).

The ADI gathers information, and using the ICT platform implemented for the BeyondSilos project, evaluates the case, prescribes an intermediate level of assistance requiring three visits a week by a specialised nurse taking care of dressing wounds, physiotherapist for rehabilitation, as well as social support for washing the patient. The new, web-based platform of the Salerno Local Health Authority saves time, and the new evaluation process increases the level of accuracy in the appropriateness of the prescription. He knows that his colleagues in the nearby city of Napoli have to prepare a lot of paper work to be submitted to the appropriate department, expecting a decision on the process that might take up to one month. On the contrary, 48 hours after the request, the ADI is already activated, and a care plan is dispatched, with the accesses requested. Magaldi life, the new Local Health Authority subcontractor, delivers the care, and doctor Esposito visits Pasquale twice a month. He is on a heavy therapy, including nine drugs for his conditions. Also he complains a lot about pain. Things are slowly improving for Pasquale, who now can move a little more, but he is always in pain. Dr Esposito reduces visits down to one every two months, because the ASL, after re-evaluation, has reduced the intensity of care from intermediate to low, which includes fewer visits by the physicians, nurses and rehabilitator. It has happened a lot of times before; to balance the internal budget, the ASL has to reduce the intensity of care to those patients that are improving, in order to have resources for new cases. This time Dr Esposito has the possibility to control remotely the biomedical parameters of Pasquale, using the telemedicine kit that is provided by BeyondSilos so he feels safer. That month, though, Dr. Esposito finds that Pasquale's blood pressure is no longer controlled, and that glycaemia, as reported by the system, is also increasing. Two weeks later, Pasquale is gaining more weight: in a week he has gained 5 kg. Dr Esposito decides to pay an extra visit, and finds that Anna has given pain killers to Pasquale for two months now. The drugs are interfering with Pasquale's medications, and the risk factors are no longer in control. One more week and Pasquale would have had accessed the emergency room, for a decompensated heart failure. This time, though, Dr. Esposito intervenes, and adjust therapy so that in one week Pasquale loses all the extra fluids he gained. A visit to the hospital emergency room has been saved for Pasquale.

# 3.9 Domain 1: Kinzigtal

## **3.9.1** Description of the health and social problem

In Kinzigtal we will include care recipients with COPD, type 2 diabetes, cardiovascular diseases and stroke in the BeyondSilos evaluation. For a general description of the diseases and social situation, please see section 3.3 and 3.4.

## **3.9.2** Quantification of the burden of disease / health problem and social problem

In 2012, 20.6% of the German population (80.3 million in 2012) were aged 65 years and older, and 5.4% were 80 years and older. Of the population aged 16 to 64 years, an estimated 30.3% had at least one (self-reported) long-standing illness or health problem in 2013. Based on the occurrence of 14 self-reported chronic conditions, it has been estimated that approximately 42% of the German population aged 50 years and older suffer from multimorbidity, i.e. have been diagnosed with at least two of these 14 conditions. Moreover, the ageing of its population and the changes in life style will lead to increasing numbers of patients with multiple chronic diseases. These patients require care that is better coordinated



across different providers and sectors. Consequently past healthcare reforms in Germany have addressed the fragmentation of care, aimed to improve care for people with chronic diseases and strengthening integrated care.

Relating to diabetes mellitus, in 2013 there were 107 patients out of 23,556 in Kinzig valley who were under medical treatment by a physician of Gesundes Kinzigtal and with diabetes type 1 diagnosis (E10) and 1,750 with type 2 diagnosis (E11). For type 1, most of them were male patients aged between 50-54 or 75-79. Prevalence rate for diabetes type 1 was 0.8% in 2013 in the region of Kinzig valley. Peak incidence of diabetes type 2 patients was between 74 and 79 years old, and female. Prevalence rate of diabetes type 2 in Kinzig valley was 9.1% for the year 2013.

For strokes in the year 2013, there were 221 new incidents (I63, I64). Most patients suffer from stroke between 70-89 years, with no relevant percentage weight between male and female. Prevalence rate was 1.1% for I63 and 0.9% for I64.

For CHF (I50), latest data contain 751 new incidents. 440 of them were female patients.

696 patients of Gesundes Kinzigtal physician practices had 2013 COPD diagnosis (J44). There were no significant differences between male or female incidence.

Relating to CVD (I20-I25), in Kinzig valley 494 new cases appeared. More than the half of them were male.

For all chronic diseases, a small increase of prevalence rate can be seen in comparison to the last years.

Approximately 10 - 15% of this target group have social needs such as meals on wheels and housekeeping, and receive them from professional social care providers. Social needs in terms of nursing are required for about 70% of persons with chronic conditions.

## **3.9.3** Management of the health and social problems

During the 2000s, Germany introduced various legal and regulatory measures to better address chronic disease, although it has yet to develop an overarching, integrated national strategy that spans the continuum from health promotion and disease prevention to the management of complex conditions and palliative care. Currently structured care or disease management programs (DMPs) represent the principal regulatory and policy framework for chronic disease management in Germany. The nationwide introduction of DMPs can be viewed as one of the most important developments with regard to care of patients with chronic health problems in German health systems (Ettelt et al. 2006). Participation in DMPs is voluntary for patients and providers. Participation is possible for Statutory Health Insurance members with a chronic disease and providers who meet the requirements set out in the regulations. Patients wishing to take part have to choose a physician (usually GP) who then acts as the coordinator. Main strategies of DMPs involve elements of self management support, delivery system design, decision support and clinical information systems.

DMPs involve coordinated treatment and care across different providers on the basis of scientific and upto-date evidence. DMPs exist for diabetes type 1 and 2, asthma, breast cancer, coronary heart diseases and COPD, and follow national guidelines. See Gemeinsamer Bundesausschuss, Richtlinie des Gemeinsamen Bundesausschusses zur Zusammenfassung der Anforderungen an die Ausgestaltung von Strukturierten Behandlungsprogrammen nach §137f Abs. 2 SGB V (<u>https:// https://www.gba.de/downloads/62-492-918/DMP-A-RL 2014-06-19.pdf</u>)

In Germany, social assistance is delivered by private providers or church owned agencies; there are no public entities for this service. Social services such as meals on wheels, housekeeping, assistance in going shopping, or support in administrative formalities are offered by third sector. In general, the offer of



social assistance agency is very big. Social assistance also includes ambulatory nursing. Home care health services are under the organisation of health providers.

Services are paid by sickness funds or nursing care insurance. The decision for such services is made by the medical service of the health funds which assess the needs of the patient. The care plan is set up by social assistance in cooperation with the responsible physician (usually GP). But in reality, those two sectors work separately with little communication between each other. For example, wound management requires a coordinated treatment between social and health care sector, but often the GP tries to take over wound management on his own.

Gesundes Kinzigtal offers specific healthcare programmes in which patients with chronic conditions can be enrolled. The primary goal of these programmes is to improve patients' overall health status and increase their quality of life, thus reducing interventions such as practice visits or hospital admissions that would be necessary without the improved health status. Social interventions could maybe also be reduced, but there is no valid data for this conclusion yet. To achieve maximum effectiveness, Gesundes Kinzigtal's care and preventive programmes target common chronic diseases with a high impact on patients' health status, and against which effective interventions are available. Most of the programmes are characterised by a cross sectional, interdisciplinary treatment. For example, for heart failure there is an integrated service between GP and different specialists such as cardiologist, psychologist; in addition, there are nutrition classes held by a dietician, and physiotherapy. For patients who have been identified in the initial health check-up of being at risk for certain diseases, Gesundes Kinzigtal offers ad hoc programmes for primary, secondary or tertiary prevention, i.e. to prevent or to postpone the onset of these diseases. For patients with chronic diseases such as diabetes, programmes are aimed to prevent or delay the onset of long term complications of the disease, such as the occurrence of retinopathy, diabetic foot, renal failure, or cardiovascular diseases. All these programmes are developed on evidence based guidelines, and constantly checked and developed further after their implementation, following the "plando-check-act" scheme.

The healthcare programme "Healthy Weight" for example is intended for patients with different risk factors for the development of the metabolic syndrome. Among these risk factors are obesity, diabetes, hypertension and low HDL cholesterol or high LDL-cholesterol. The main objective of the programme is to prevent or stop the development of T2DM and its complications. In order to achieve this objective, Gesundes Kinzigtal supports and motivates their members in changing their lifestyles. The professional accompaniment consists of specialised comprehensive medical care, nutrition counselling, and sports activities, especially focused on obese patients. By means of this healthcare programme, the quality of life can be improved. The approach to reach these targets is based on the biopsychosocial model, developed by Engel during the 1970s (Pauls, 2013). The keynote of this approach includes biological, psychological and social conditions which need to be considered during the development and progression of a (chronic) disease. The biopsychosocial model emphasises the active role of the individual for protection and promotion of health. To support the active role of the patient is an important part of the programme "Healthy Weight".

Dealing with a health problem of a family member is quite a challenge. There is only little structured involvement in the care process, because usually family members do not have enough expertise. Some regions organise self help groups for family members to get advice and support.

To give a clear overview of the foreseen improvements of interaction between actors / sectors after the new BeyondSilos service has been introduced in Kinzigtal, Table 6 shows the current interaction between sectors (usual care) and the foreseen interaction between sectors (new care) after BeyondSilos has been introduced. Any improvements from "usual care" to "new care" have been highlighted and underlined in the table. The definition of the different levels is provided in section 3.5 above.

# D6.2 Interim Evaluation Report



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Health services						
Usual care	High:	Medium:	Low:	Low:	Medium:	Low:
	Established central electronic patient record for GPs and specialists.	Communication via phone call, telefax or personal contact. Usually there is more information requested from social care to healthcare than the other way round.	Interaction only in case patient wants to; he is the interface between both.	Interaction very rare, working usually separately to the patient; no information transfer except a prescription provision from a GP or specialist for physiotherapist for example.	Practice visits, phone calls or home visits. Interaction with practice assistance is sometimes higher than short treatment time in front of physician.	Interaction only in case patient wants to; he is the interface between both.
New care	No changes:	<b><u>High</u>:</b> Better information quality based on data exchange from both, and access to central electronic patient record.	No changes:	No changes:	High: Better information quality and maybe more time for care recipient based on information input from social care services via common electronic health record.	Medium: Better information quality based on input from social care services, especially when family is involved in care processes.

Table 6: Kinzigtal: Interactions and integration within and between sectors (comparison between usual care at start vs new care at mid-term)



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Social services						
Usual care	Low: Communication via phone call, telefax or personal contact in case information about patient is needed. GP is in gatekeeper position and delegates services. There is more often an information request from social care provider to health care provider.	Medium: Interaction within institution via meetings, common documentation system.	Medium: Interaction via routine phone calls or personal contact in case of support of social services.	Low: Interaction very rare, working usually separately to the patient; no information transfer directly. Mostly information transfer via care recipient.	Medium: Visits by ambulant nurse and phone calls, consultancy meetings.	Medium: Interaction is in routine way because most of care recipients need assistance from family members to discuss care plans etc. Information exchange via phone calls or personal contact.
New care	Medium: Better information quality based on data exchange from both and access to central electronic patient record.	High: Better information quality based on data exchange from both and access to central electronic patient record. Less paper documentation leads to fewer mistakes, and finally better communication internally.	No changes:	No changes:	No changes: <u>Added value</u> : better information quality and more time for care recipient based on information input from healthcare such as medication plan via common electronic health record.	No changes: <u>Added value:</u> better information quality to family members based on information input from healthcare such as medication plan via common electronic health record.



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Third sector						
Usual Care	Low: Interaction only in case patient wants to; he is interface between both.	Medium: Interaction via routine phone calls or personal contact in case of support from social services.	Medium: Internal interaction within one institution is well established, but between two third sector institutions interaction is low.	Low: Interaction very rare, working usually separately to the patient; no information transfer directly. Mostly information transfer via care recipient.	Medium: Interaction is more in spontaneous manner, little in routine workflow via phone calls or home visits.	Low: Interaction and involvement of family members is more in spontaneous manner, little in routine workflow via phone calls or home visits. But less integration than with patient directly.
New care	No changes:	No changes:	No changes:	No changes:	No changes:	No changes:
Other providers	•	•			•	
Usual care	Low: Interaction very rare, working usually separately to the patient, no information transfer except prescription provision, for example for a physiotherapist from GPs or specialists.	Low: Interaction very rare, working usually separately to the patient, no information transfer.	Low: Interaction very rare, working usually separately to the patient, no information transfer.	Low: Interaction very rare, working usually separately to the patient, no information transfer directly. Mostly information transfer via care recipient.	Medium: Interaction via visits, phone calls. Personal contact in case there is a prescription from GP.	Low: Interaction and involvement of family members is more in spontaneous manner, little in routine workflow via phone calls or home visits. Family members are only involved where patient is very disabled.
New care	No changes:	No changes:	No changes:	No changes:	No changes:	No changes:



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Person- care rec	ipient					
Usual care	Medium: Practice visits, phone calls, prescriptions but usually no written information available for patient.	Medium: Visits by ambulant nurse and phone calls.	Low: Interaction is more in spontaneous manner, little in routine workflow via phone calls or home visits.	Low: Interaction via visits, phone calls. Personal contact in case there is a prescription from GP.	Low: Interaction spontaneously or in self help groups in personal contact.	Medium: Where family network is well established information exchange in personal contact or phone calls frequently. Low interaction if relations within family are few.
New care	High: Better information quality based on information input from social care services. Feeling more safety concerning home care.	High: Better information quality and more time for care recipient based on information input from health care, such as medication plan via common electronic health record. Feeling more safety concerning home care.	No changes:	No changes:	No changes:	No changes:



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Family –entourage						
Usual care	Low:	Low:	Low:	Low:	Medium:	Medium:
	Interaction only in case	Interaction is in	Interaction and	Interaction and	where family network	In case family network
	patient wants to; he is	routine way because	involvement of	involvement of family	is well established,	is well established,
	interface between	most of care	family members is	members is more in	information exchange	information exchange
	both.	recipients need	more in	spontaneous manner,	in personal contact or	in personal contact or
		assistance from family	spontaneous	little in routine	phone calls	phone calls
		members to discuss	manner, little in	workflow via phone	frequently. Low	frequently. Low
		care plans etc.	routine workflow	calls or home visits.	interaction if relations	interaction if relations
		Information exchange	via phone calls or	Family members are	within family are few.	within family are few.
		via phone calls or	home visits	involved only where		
		personal contact.		patient is very disabled.		
New care	Medium:	Medium:	No changes:	No changes:	No changes:	No changes:
	Better information	Better information				
	quality based on	quality to family				
	information input from	members based on				
	social care services	information input				
	when family is involved	from health care such				
	in treatment process.	as medication plan via				
		common electronic				
		health record.				



# **3.9.4** The ICT solution supporting integrated care (including technical characteristics of the service)

The technical part will link the social care documentation system called AscleonCare with the electronic patient record called CGM net. To connect the social care documentation software AscleonCare and the electronic patient record (CGM net) of Gesundes Kinzigtal, a special interface is needed. This interface will be done via client software DocAccess. DocAccess provides a protocol in which the relevant data of the social care sector is written in and translated.



**Usual Care** 

**New Care** 

Figure 5: Kinzigtal: New care v. usual care

Social care staff are able to send relevant data into the electronic patient record via DocAccess. This data can then be seen by the GPs in the electronic patient record. On the other hand, the social carers have access via DocAccess to electronic patient record, and are able to see some information of the GPs. On the AscleonCare platform, a special button is created to start the Doc access interface.

Electronic patient record is used by social care professional, GPs and their practice assistance.

The technology used is fully developed. The software runs on tablets and PCs of home care unit. Hardware requirements are:

- Display: 25,7 cm (10,1 Zoll) touchscreen.
- Resolution: 1280 x 800 Pixel.
- Processor: Intel Atom Z3735F (standard).
- Graphic: Intel HD Graphics.
- Main memory: 2 GB.
- Store: 16/32 GB.
- Operating system: Win 8.1.
- Communication: WLAN 802.11 b/g/n, Bluetooth.

## 3.9.5 Requirements for use of the ICT solution

Internet connection via WLan or mobile connection (and electricity) is needed to use the ICT system.

To use the ICT system you need hardware like PCs, laptop or tablet with requirements see above. CGMnet Software powered by Compugroup medical, AscleonCare powered by medical networks and DocAccess powered by Compugroup medical.



To set up the BeyondSilos pilot site infrastructure, only training for social care staff is necessary, because they are the only group that need to work with the new software, and have changes in their workflow management. A two day training session for social care staff is necessary to receive training for the AscleonCare software, and operate with the new service. Gesundes Kinzigtal is responsible for the organisation of the training course, and also provides the location. The training course itself is held via web presentation and online training units by Medical networks, which is the provider of AscleonCare.

GPs are already used to working with an electronic patient record.

#### 3.9.6 Case description

Manfred Armbruster is a 76-year-old retired engineer with chronic heart failure, high blood pressure and diabetes mellitus type2. Because of his diabetes, he is suffering a chronic wound on his left foot. He lives with his 73-year-old wife who tries to care for him as much as possible. While herself suffering from arthritis, she feels overstrained with this job. They live in a house on the rural outskirts without any neighbourhood and are increasingly housebound due to their illnesses. They are determined to remain independent; their grandson, who lives 300 km away, cannot look after them on a weekly basis, and supports them in only a few activities. As a retired engineer, the patient will be covered by Statutory Health Insurance (SHI), while paying a reduced monthly rate for pensioners. Because of his health problems, he is also eligible to participate in DMPs for chronic heart failure, which is offered by his local GP Dr. Volk. As the patient and his wife become increasingly housebound, the GP will visit them at home, which takes about 20 to 24 minutes drive by car, to monitor their chronic conditions regularly. Because of the exacerbation of his chronic conditions, an outpatient nursing agency is hired to perform a geriatric assessment in order to identify health problems and other social care needs. Mr. and Mrs. Armbruster need meals on wheels and social care staff who do housekeeping. Furthermore, Mr. Armbruster needs assistance in bathing and taking medication. The wound on the left foot caused by diabetes needs a regular wound management

**Sabine Dold** is the responsible social care professional for Mr. and Mrs. Armbruster, and visits them on a daily base for medication and once a week for bathing and wound management. Her essential work tool is a tablet, which she switches on every time she enters Armbruster's house. It shows route planning, patient's profile and requested services. But the most important feature is access to the electronic patient record of Mr. Armbruster's GP. Instead of carrying a not updated printed sheet of paper and wasting time trying to reach Dr. Volk by phone to ask for updated documents, her tablet displays the latest medication plan with a few clicks. After giving medication and checking blood pressure, Mrs. Dold takes a photo with the tablet camera and uploads this data directly into electronic patient record of Dr. Volk. In his practice, Dr. Volk regular looks at the patient record of Mr. Armbruster and checks vital parameter and examines wound healing by looking at photo documentation. Because of exacerbation of Mr. Armbruster's wound, the medication plan must be adapted. With this innovative and easy procedure of exchanging data, Dr. Volk can reduce home visits to Mr. and Mrs. Armbruster and gains more time for his patients at his practice.

## **3.10** Domain 1: Amadora

#### 3.10.1 Description of the health and social problem

In Amadora, the target group of BeyondSilos is composed of the clients of Home Care Support of Misericordia of Amadora, which means 150 end users over 65 years old, living in their homes. It will include care recipients with the following main diseases: COPD, diabetes, stroke, and cardiovascular disease. Along with these health problems, there are other diseases among the target group, such as mental disorders (Parkinson and Alzheimer), diseases of the musculoskeletal system and connective tissue, influenza and pneumonia, malignant neoplasms, paraplegia, and chronic lower respiratory diseases.



In terms of social needs, 100% of the end users are dependent on the social services that Misericordia of Amadora delivers daily, due to their lack of autonomy and isolation. These services are focused on ADL and IADL, such as delivering meals, doing housework, and taking medications.

They are therefore to be considered affected by "complex situation" or "being multiproblematic patients", the special target of BeyondSilos Project and new integrated care actions.

# **3.10.2** Quantification of the burden of disease / health problem and social problem

Amadora's territory has 23.8 km<sup>2</sup> for a population of 175,558 inhabitants, which makes Amadora Council the region in Portugal with the highest demographic density (7,363 people/km<sup>2</sup>). Amadora is a much challenged territory, according to the following indicators:

- 16,000 unemployed people.
- 30,000 with low education skills.
- 15% of young people.
- 35,000 immigrants, 20% of the universe.
- 19% aged over 65.
- 42% aged over 75.

Concerns the more specific indicators related with health and social needs in BeyondSilos, Amadora faces the following challenges in terms of mortality per 100,000 inhabitants

- Higher representativeness in terms of years of life potentially lost (5,119) compared with the national average (4,354).
- High proportion of people suffering from Diabetes Mellitus (7.2%) between 20-79 years old.
- High proportion of people suffering from arterial hypertension (19.8%).
- Higher proportion of deaths caused by stroke (17.7) compared with the national average (11).
- Higher proportion of deaths caused by ischemic cardiac disease (15.6) compared with the national average (10.7).
- Highest national proportion of people suffering from tuberculosis (49.1).
- Higher proportion of deaths caused by cervical cancer (20.4) compared with the national average (3.4).
- Higher proportion of deaths caused by cervical and rectal cancer (9.2) compared with the national average (8.5).
- Higher proportion of deaths caused by HIV (21.3) compared with the national average (7).
- Higher proportion of deaths caused by breast cancer (48.6) compared with the national average (15.3).

Regarding morbidity indicators, Amadora faces the following challenges:

- Higher incidence of stroke (33) compared with the national average (31.4).
- Higher incidence of stroke before the age of 65 years (13.9) compared with the national average (9.4).
- Higher incidence of heart failure before the age of 65 years old (8) compared with the national average (16.1).

In Amadora there are well identified priorities regarding the most relevant diseases (cancer, cardiovascular disease, HIV, diabetes) that significantly increase in association with poverty. Health services have well defined target for improvements of outcomes, e.g. increase of screenings, reducing mortality for the specific diseases, increase in literacy on the specific diseases among the target groups.

Specifically related to BeyondSilos, Amadora has prioritised and defined strategies to monitor strokes and diabetes as follows:



Priorities	Strategies
	To enlarge literacy among the critical target group.
Stroke	To invest in and enlarge the number of preventive diagnoses.
	To invest more in primary and secondary care.
	To enlarge the number of diagnoses to a prevalence of 8%.
Diabetes Mellitus	To enlarge the screening ratio for secondary care and the screening for diabetic retinopathy.
	To enlarge literacy among the critical target group.

# **3.10.3** Management of the health and social problems

Amadora deployment site, within the frame of BeyondSilos, is focused on the services delivered at home, specifically on the services provided by Misericordia of Amadora Home Care Support. In terms of usual care, there are currently no integrated services delivered at home. Services delivered are based mainly on social needs, such as hygiene, food, and medication monitoring. The ICT tools available are based just on teleassistance; telemonitoring is not provided at all.

BeyondSilos thus represents a huge increase of quality, safety and gains of scale in terms of time saving and operability due to the integration of services, ICT components (teleassistance + telemonitoring + online portal). With BeyondSilos, there is a chance for people to stay longer in their homes instead of moving to nursing homes and/or day care centres, avoiding financial costs and deterioration of quality of life.

The main differences in the new services start during the referral process that can be addressed either to the Local Council for Social Action (composed of all the relevant stakeholders in Amadora, representatives of public sector / non-profit and profit) or directly to SCMA (Santa Casa da Misericórdia da Amadora).

After that, the Coordination Team of BeyondSilos alongside the Home Care Support Team will evaluate the situation; if the citizen meets the inclusion criteria, he/she will be enrolled in BeyondSilos process.

Local Council for Social Action will record the participation of all the key health and social care actors, which include hospital, healthcare and social security, that will take part during the time that the client is enrolled.

Besides the integration of social and health care stakeholders, ICT improvement will be another key element in the process, with the following technical solutions:

- Tele-Assistance: panic button alarm and direct link with Home Care Support Team, together with a Contact Centre available after the end of the business day and during the weekend.
- Telemonitoring: blood glucose, blood pressure, weight, temperature.
- Home Care Portal: this platform will record all the social and health incidents with different permissions depending on the types of actor; this will improve the circulation of relevant information regarding the care actions and cooperation between informal carers and care givers.
- B-Learning Tool to train formal and informal carers.

Amadora deployment site will involve formal and informal carers as follows:

- Formal Carers:
  - Coordination Team: Amadora Municipality Team & Misericordia of Amadora Team; Project Manager; Home Care Support Coordination; nurses.
  - - Operational Team: nurses, physiotherapists and family helpers.



- Informal Carers
  - Relatives (115 relatives enrolled)
  - Volunteers (15 Volunteers enrolled)

Amadora has identified the care recipients to be part of the BeyondSilos service provision in two different ways, according to the integrated common care pathways:

**Short-Term**: three different entry points for patients in an acute situation after hospitalisation, after surgery, because of an early discharge, or any acute event, including social issues, and self-referral:

- Discharge from the hospital / healthcare centre after a hospitalisation, surgery, or early discharge.
- Referral from the CLAS (Local Council for Social Action), or any related organisation, namely Social Security and Amadora Municipality:
  - identification of elderly people living alone in need of home care support due to several and emergent constraints related to mobility and/or subsistence; and/or
  - identification of citizens being monitored for social & health reasons by other organisations, but who could benefit from BeyondSilos workflow.
- Referral by citizen him/herself, or by any relatives: incapacity to continue living without social & health support.

When the actors above identify a person with an acute episode regarding social and/or health care, they can trigger the process of referral to SCMA Home Care Support Service (HCSS). After that, the Coordination Team of HCSS, composed of nurses and social workers, will evaluate the situation, and in case of need, enrol the client into BeyondSilos workflow. If the Coordination Team considers that the potential care recipient needs any different type of response, such as permanent assistance, or partial but on-site assistance, they can refer to other social & health services of SCMA, such as nursing homes, continuing care unit, or day care centre.

**Long Term**: three different entry points for CRs (Care Recipients) with a chronic situation: worsening of health status: heart failure; COPD; and/or worsening of social situation: living alone with no primary or secondary network; lack of means of subsistence or mobility:

Discharge from the nursing home / day care centre / care continuing unit: Once the BeyondSilos
deployment site supports the increase of services at home due to better quality in terms of
improvement of skills in professionals domain (training) and also due to ICT components (teleassistance improvement and tele-monitoring), it will allow some people who currently must live
institutionalised to return to their homes and have access to the services they need without leaving
home.

Table 7 below identifies the main gains from the transition from usual care to the new care regarding what is delivered at home.



Categories	Usual Care	New Care (Integrated Care)
Domain of services delivered	Social Services	Social and health services
Actors involved	Formal carers: social workers; family workers. Informal carers: relatives and volunteers.	Formal carers; social workers; family helpers; nurses; physiotherapists; physicians.
Type of services delivered	Meals; cleaning; medication monitoring; tele-assistance.	Meals; cleaning; medication monitoring; tele-assistance; telemonitoring (weight; blood pressure); Contact Centre.
Technology	Tele-assistance	Tele-assistance and telemonitoring.
ICT tools	Panic button	Panic button; smartphones; tablets; online platform; e-learning tool
Process management	On site	On site and remote
Information handled in the context of service delivery / use	Homemade database Reports on paper No strategic and crossed Planning of the Home visits	Electronic and structured database. Automatic and electronic reports. Strategic and electronic planning of the home visits.

Table 7: Amadora: Expected gains from the move to the new care services

To give a clear overview of the foreseen improvements of interaction between actors / sectors after the new BeyondSilos service has been introduced in Amadora, Table 8 shows the current interaction between sectors (usual care) and the foreseen interaction between sectors (new care) after BeyondSilos has been introduced. Any improvements from "usual care" to "new care" have been highlighted and underlined in the table. The definition of the different levels is provided in section 3.5 above.



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Health services	•	•	•	•	•	•
Usual care	Medium:	Low:	Medium:	Medium:	Low:	Low:
	Misericordia of Amadora includes a pool of primary and secondary care services (medical clinic; long term care unit; nursing homes; day care centres; unit for the rest of the carer). However, the services delivered at home do not include integration of services.	Services delivered at home do not include integration of services (social, health services, technology).	Misericordia of Amadora includes a pool of primary and secondary care services (medical clinic; long term care unit; nursing homes; day care centres; unit for the rest of the carer). However, services delivered at home do not include integration of services.	In Amadora Council there is a solid network of different health providers (public sector, third sector, private sector) but there is no integration of services at home.	Public health services in Amadora are either busy or distant from the patient's home; third sector health services are always busy; private health services are expensive.	Public health services in Amadora are either busy or distant from the patient's home; third sector health services are always busy; private health services are expensive.
New care	High: Integration of services at home (social & health services) supported by ICT tools that allow on- time monitoring of the health situation and remote control.	High: Integration of ICT tools on the planning and report of social services (online platform).	High: Integration of services at home by Misericordia of Amadora (social & health services) supported by ICT tools that allow on- time monitoring of the health situation and remote control.	<u><b>High:</b></u> Increasing the possibility of adapting the model in the future.	High: Increasing the possibility to receive primary care at home, avoiding queues and other direct and indirect costs (transport) at the same time that safety and comfort increases due to on-time monitoring of health situation.	High: Increasing the possibility to receive primary care at home, avoiding queues and other direct and indirect costs (transport) at the same time that safety and comfort increases due to on- time monitoring of health situation.

Table 8: Amadora: Interactions and integration within and between sectors (comparison between usual care at start vs new care at mid-term)



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Social services						
Usual care	Low:	Medium:	Medium:	Medium:	Medium:	Medium:
	Services delivered at	Some formal	Some formal agreements	Great level of	Some formal	Some formal
	home do not include	agreements / rules	/ rules are in place.	interaction between	agreements / rules	agreements / rules
	integration of services	are in place.		all the providers	are in place.	are in place.
	(social, health services,			involved within the		
	technology).			provision of care,		
				either from the		
				health or the social		
				side, but without		
				integration of		
				services at home.		
New care	<u>High:</u>	<u>High:</u>	High:	<u>High:</u>	<u>High:</u>	<u>High:</u>
	Integration of ICT Tools	Formal agreement	Formal agreement in	Increase in the	Formal agreement in	Formal agreement in
	on the planning and	in place. Clear	place. Clear workflow	possibility of other	place. Clear workflow	place. Clear
	report of social services	workflow between	between actors defined;	organisations to	between actors	workflow between
	(online platform).	actors defined; ICT	ICT solutions are	adopt the model in	defined; ICT solutions	actors defined; ICT
		solutions are	positively integrated and	the future.	are positively	solutions are
		positively	are part of the work		integrated and are	positively integrated
		integrated and are	routine.		part of the work	and are part of the
		part of the work			routine.	work routine.
		routine.				



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Third sector						
Usual Care	Medium: Misericordia of Amadora includes a pool of primary and secondary care services (medical clinic; long term care unit; nursing homes; day care centres; unit for the rest of the carer). However, services delivered at home do not include integration of services.	Medium: Some formal agreements / rules are in place.	Medium: Some formal agreements / rules are in place.	Low: Only spontaneous or informal integrated practices. No formal agreements in place.	Medium: Some formal agreements / rules are in place.	Medium: Some formal agreements / rules are in place.
New care	High: Integration of services at home by Misericordia of Amadora (social & health services) supported by ICT Tools that allow on- time monitoring of the health situation and remote control.	High: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	High: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	High: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	High: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	High: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage		
Other providers								
Usual care	Medium:	Medium:	Medium:	Medium:	Medium:	Medium:		
	In Amadora Council there is a solid network of different health providers (public sector, third sector, private sector), but there is no integration of services at home.	Great level of interaction between all the providers involved within the provision of care, from both the health and social side, but without integration of services at home.	Some formal agreements / rules are in place.	Strong network of third sector organisations and public, but weak with private companies.	Strong network and close relationship between third sector organisations and public, but weak with private companies.	Strong network and close relationship between third sector organisations and public, but weak with private companies.		
New care	High: Increase in the possibility of adopting the model in the future.	High: Increase in the possibility of other organisations to adopt the model in the future.	High Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	No changes	No changes	No changes		



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage		
Person- care recipient								
Usual care	Low: Public health services in Amadora are either busy or distant from the patient's home; third sector health services are always busy; private	Medium: Some formal agreements / rules are in place.	Medium: Some formal agreements / rules are in place	Low: Only spontaneous or informal integrated practices. No formal agreements in place.	N/A	N/A		
	expensive.							
New care	High: Increase in the possibility to receive primary care at home, avoiding queues and other direct and indirect costs (transport), at the same time increasing safety and comfort due to on- time monitoring of health situation.	High: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	High: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	No changes	No changes <u>Added value:</u> Increasing comfort and safety and quality of life through the possibility of monitoring the health condition.	No changes <u>Added value:</u> Increasing comfort and safety and quality of life through the possibility of monitoring the health condition.		



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage		
Family –entourage								
Usual care	Low: Public health services in Amadora are either busy or distant from the patient's home; third sector health services are always busy; private health services are	Medium: Some formal agreements / rules are in place	Medium: Some formal agreements /rules are in place	Low: Only spontaneous or informal integrated practices. No formal agreements in place.	N/A	N/A		
Now caro	expensive.	llich.	lliah.	No changes	No changes	No changes		
New care	Hign: Increase in the possibility to receive primary care at home, avoiding queues and other direct and indirect costs (transport), at the same time increasing safety and comfort due to on- time monitoring of health situation.	Hign: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	Hign: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.	No changes	Added value: Increasing comfort and safety and quality of life through the possibility of monitoring the health condition.	Added value: Increasing comfort and safety and quality of life through the possibility of monitoring the health condition.		



# **3.10.4** The ICT solution supporting integrated care (including technical characteristics of the service)

A full description of the ICT solution can be found in deliverables D3.2 BeyondSilos Service specification and D4.2 BeyondSilos Prototype system.

The ICT solution (technology) implemented in Amadora deployment site comprises the following main elements:

- eLearning integrated solution
- Tele-assistance and telemonitoring solution
  - Teleassistência Patients with fixed line PT.
  - True Kare Patients with mobile line PT.
  - Smarthealth.
- Portal PAD (Portal de Assistência Domiciliária)

#### **3.10.5** Requirements for use of the ICT solution

With regards to training to use the ICT tools, Portugal Telecom provided training on tele-assistance operability, telemonitoring interaction, and online portal monitoring to all the Coordination Team and Operational Team.

To implement the solution as a whole, there are some initial activities required for each of the services considered in the pilot:

#### 1. Tele-assistance

 Create the exclusive PT's phone number for Santa Casa da Misericórdia and associate it to teleassistance service.

#### 2. Equipment

- Gather and collect the measurement equipments and telephones.
- Register the clients on PAD + Smarthealth.
- Set up the exclusive Santa Casa's telephone number
- Telemonitoring Equipments:
  - The ForaCare W310 balance
  - the ForaCare D40 Series sphygmomanometer,
  - the thermometer ForaCare IR20 thermometer,
  - the SmartPhone

#### 3. FORMARE: LMS -Learning Management System

- Parameterise Santa Casa da Misericórdia on the system.
- Assure the users creation.

There are some other technical and generic requirements, in a macro-view, to supply the solutions:

- E-learning integrated solution:
  - Internet access.
  - Access to a PC.
  - Adjusted contents.
- Tele-assistance and telemonitoring
  - Patients with PT's fixed-line network; and
  - Fixed-line telephone equipment (Teleassistência); or


- Patients with PT's Mobile line (MEO); and
- Mobile phone equipment (True-Kare)
- Portal PAD (Portal de Assistência Domiciliária)
  - Internet access.
  - Access to a PC.
  - Web Portal.

#### Specific technical requirements

- SmartLiving (Smarthealth) infrastructure's layers and requirements:
  - Application server:
    - CPU: 2 Core;
    - RAM: 16GB;
    - HDD: 100GB;
    - SO: Windows Server 2008 R2 x64 Standard Edition;
    - Outro: IIS 7 com .NET Framework 4.5.
  - Data base server:
    - CPU: 4 Core;
    - RAM: 16GB;
    - HDD: 500GB;
    - SO: Windows Server 2008 R2 x64 Enterprise Edition;
    - SGBD: SQL Server 2008 R2 x64 Enterprise Edition.
  - RA server:
    - CPU: 2 Core (Intel E5-2680 @ 2.7GHz);
    - RAM: 4GB;
    - HDD: 100GB;
    - SO: RedHat Enterprise Linux 6.
  - SDP server:
    - CPU: 2 (Intel E5-2680 @ 2.7GHz);
    - RAM: 4GB;
    - HDD: 500GB;
    - SO: RedHat Enterprise Linux 6;
    - SGBD: PostgreSQL 9.2.
- Client's machines network requirements:
  - Connection / internet: minimum of 1Mbps.
- Infrastructure "backend" (servers) network requirements:
  Connection: minimum of 100Mbps.
- Computer / tablet client's infrastructure:
  - Browser: IE9+, Chrome, Firefox or Safari.

## 3.10.6 Case description

Manuel António is a 70 year old man who lives alone and suffers from diabetes and arterial hypertension. Due to these problems, and because he lives alone and is very anxious, he used to stay in the nursing home of Misericordia of Amadora.

Manuel needs to monitor his blood sugar levels and blood pressure.

Nowadays, he lives at home and receives both social and health care from Misericordia of Amadora. The Coordination Team of BeyondSilos enrolled him in the service process model of BeyondSilos and defined a personalised care plan for him that encompasses social services (hygiene, cleaning, food) and health services (vital signs monitoring and medication). He is visited three times a day by family workers and



nurses. At the same time, the Coordination Team of the Home Care Support of Misericordia monitors the health and clinical situation from a remote perspective, using the online platform that gathers all the critical incidents for each client. Every time an alarm is triggered, the Operational Team, composed of nurses, social workers and family workers, immediately contact Manuel and go to his home to check the situation and evaluate if it can be solved there, or if he need to go to the hospital. The contact centre is always there to intervene if the Operational Team cannot for any reason.

After he moved to his house, he became less anxious, because he feels more secure about his levels of sugar and blood pressure. Every time he wants, he just turns on the TV and can see his clinical status. At the same time, he became more comfortable, because he is in his natural habitat.

## 3.11 Domain 1: Sofia

## **3.11.1** Description of the health and social problem

As described in sections 3.3 and 3.4.

## 3.11.2 Quantification of the burden of disease / health problem and social problem

Health problems often cause reducing mobility, difficulties with everyday life activities, psychological problems such as a fear and anxiety. The care recipients need social work, personal assistance and home support. Social problems which are not solved lead to worsening health problems. For example: deprivation, diet, lack of appropriate environment.

In Bulgaria, between 60% and 70% of all deaths are the result of cardiovascular diseases. The incidence and prevalence for cerebrovascular diseases, even with a tendency to decrease over the last few years, remain more than two times higher than the EU average<sup>30</sup>.

The prevalence of diabetes in Bulgaria is also higher than the EU average, with a tendency to decrease.

There were no exact figures found regarding the proportion of the specific target group with social needs. However, given the very high mortality rate of cardiovascular diseases in Bulgaria (obviously due to high prevalence), that affect aged people with low economic status, we can expect a very high proportion within the target group.

According to the Global Burden of Disease Study 2010 (GBD 2010):

- In terms of the number of years of life lost (YLLs) due to premature death in Bulgaria, ischemic heart disease (24.2%), cerebrovascular disease, trachea, bronchus, and lung cancers were the highest ranking causes in 2010.
- In Bulgaria, the top three causes of Disability-adjusted life years (DALYs) in 2010 were ischemic heart disease, cerebrovascular disease, and low back pain.

## **3.11.3** Management of the health and social problems

Health problems (if not emergency cases) are managed at primary healthcare level by the GP. In case of need, the patient could be directed to a specialist in a Diagnostic Consultancy Centre (primary care) or hospital (secondary care). Chronic cases are also managed by GPs in long term. There are not enough hospitals for long term care, nor are they well developed.

Social problems are independently managed by social workers (if and where available), without coordination with the GP. Social workers are usually civil servants of Social Assistance Agency, a public

<sup>&</sup>lt;sup>30</sup> Bulgarian Society of Cardiology

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body. They evaluate poverty and housing of the care recipient to decide on their social needs, and help them to manage social isolation, social support with the institutions, and malnutrition.

There is a National Health Strategy 2014-2020 and a National Programme for Prevention of Chronic Noncommunicable Diseases 2014 – 2020, which include among their priorities cardiovascular diseases in Bulgaria.

The integrated health and social care is one of the main priorities of the National Strategy for Long-term Care.

Nothing specific is offered for this health problem with regard to social assistance, so far. There is no integrated service offered to people with this health problem. Depending on the stage of the disease, the capability of the person to manage alone, and their needs, then family members could provide food, cleaning, feeding, ensure regular medicine intake, etc. Volunteer care is not very well developed in Bulgaria in this respect.

To give a clear overview of the foreseen improvements of interaction between actors / sectors after the new BeyondSilos service has been introduced in Sofia, Table 9 shows the current interaction between sectors (usual care) and the foreseen interaction between sectors (new care) after BeyondSilos has been introduced. Any improvements from "usual care" to "new care" have been highlighted and underlined in the table. The definition of the different levels is provided in section 3.5 above.

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	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage		
Health services	Health services vs							
Usual care	Low:	Low:	NA	NA	Medium	Medium		
	There are relations	Social services and			The patient has constant	The family members can		
	between different levels	health services are in			access to his GP and	discuss the disease of		
	of healthcare provided,	different silos. Any			specialist, if needed.	their relatives at their		
	but there are no	interaction is accidental.				request.		
	common databases and							
	formal agreements.							
New care	<u>High:</u>	<u>High:</u>	NA	NA	High:	High:		
	Health services are a	Social and health			The care recipient is an active	The family can rely on		
	part of an integrated	services are co-ordinated			part of his/her treatment and	constant health and		
	care plan.	via a common platform			care	social surveillance for		
	Continuous follow up of	and according to an			The patient can rely on	their relatives.		
	health status	integrated care plan			constant health and social			
					surveillance.			
Social services v	S	•	•		-			
Usual care	Low:	Low:	NA	NA	Medium:	Medium:		
	Social services and	Social services are			Care recipients receive social	Family members are		
	health services are in	provided in a			services from different	barely involved in the		
	different silos. Any	bureaucratic and formal			agencies with little	planning of social care.		
	interaction is accidental.	manner:			interaction between them.			

Table 9: Sofia: Interactions and integration within and between sectors (comparison between usual care at start vs new care at mid-term)



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage		
New care	<u>High:</u>	Medium:	NA	NA	High:	High:		
	Social and health	Different social services			The patient can rely on	The family can rely on		
	services are co-	are integrated as a part			constant health and social	constant health and		
	ordinated via a common	of an integrated care			surveillance.	social surveillance for		
	platform and according	plan.			The care recipients are	their relatives.		
	to an integrated care	Continuous social			actively involved in the	The family members are		
	plan.	support by visits and			planning and provision of	an important and active		
		phone calls			social services.	stakeholder in the		
						integrated care plan.		
Third sector vs	Third sector vs							
Usual Care	N/A	N/A	N/A	N/A	N/A	N/A		
New care	N/A	N/A	N/A	N/A	N/A	N/A		
Other providers	vs							
Usual care	N/A	N/A	N/A	N/A	N/A	N/A		
New care	N/A	N/A	N/A	N/A	N/A	N/A		
Person- care reci	pient vs			•	•			
Usual care	Medium:	Medium:	N/A	N/A	N/A	N/A		
	The patient has	Care recipients receive						
	constant access to his	social services from						
	GP and specialist, if	different agencies with						
	needed.	little interaction						
		between them.						



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
New care	High: The care recipient is an active part of his/her treatment and care. The patient can rely on constant health and social surveillance.	High: The care recipient is an active part of his/her treatment and care. The patient can rely on constant health and social surveillance.	N/A	N/A	N/A	N/A
Family –entourag	ge vs					
Usual care	Medium: The family members can discuss the disease of their relatives at their request.	Medium: Family members are barely involved in the planning of social care.	N/A	N/A	N/A	N/A
New care	High: The family can rely on constant health and social surveillance for their relatives.	High: The family can rely on constant health and social surveillance for their relatives. The family members are an important and active stakeholder in the integrated care plan.	N/A	N/A	N/A	N/A



# **3.11.4** The ICT solution supporting integrated care (including technical characteristics of the service)

A full description of the ICT solution can be found in deliverables D3.2 BeyondSilos Service specification and D4.2 BeyondSilos Prototype system.

The ICT solution targets providing integrated services to improve the following:

- Health aspects: constant follow up of regular medicine intake, pulse and blood pressure measurements, temperature of the environment.
- Social aspects: assistance in providing food, constant social support (meetings, phone calls, help).

The application is based on Android technology (for the end users) and specific vital and environment characteristics measurement hardware based on Bluetooth 4 (LE) distributed by various vendors.

A cloud computing infrastructure based on Microsoft technologies and open source products is provided as a back-end service for the day-to-day operational staff.

As with any product related to online ICT & healthcare services, the technology is constantly being improved and developed. It is in a stable release phase, but additional functionalities and improvements are being added constantly.

The solution is integrated with the call-centre infrastructure, mobile devices and desktop infrastructure with a modern cutting-edge REST based web API technology. Google services are used for file management and calendar integration; the latest Microsoft.NET integration API from Google is used.

#### **3.11.5** Requirements for use of the ICT solution

The ICT solution is designed to work with most modern web browsers, so it can be used on any desktop / mobile device for the back end, and any Bluetooth LE compatible Android device as a patient device.

Any desktop / tablet device can be used by GPs, social workers, Call Centre, administrators to access the back end ICT system. Bluetooth LE compatible Android devices are required as a patient device. Bluetooth LE protocol compatible sensors (temperature, blood pressure, glucose, etc.) are required to measure and transfer the data to the back end.

Currently we are collecting medical, environment and call centre call data. We are in the process of improving security and logging as a technical precaution.

User guides have been distributed both to personnel and care recipients, but individual training and later service desk support is needed for full familiarity with the product. Currently there is no established ITSM infrastructure (service desk, incident management, event management, knowledge base, CMS/CMDB), and the support is usually onsite which leads to a higher maintenance cost.

## **3.11.6 Case description**

Snezhana Dimitrova Georgieva is 78 with congestive heart failure (I11, I25), connective tissue disease (M47, M81) and ulcer (K29). Snezhana has used the service since May, and says it gives her confidence and peace of mind that there is someone who can monitor her vital signs daily, respond to her medical condition, and give adequate advice on how to act at the event of a health problem. She underlines the important social aspects that are improved with the communication between her and the Call Centre, as well as visits by social assistants. The BeyondSilos integrated care for Snezhana and all those involved provides: measurement of blood pressure, pulse, temperature of the environment, together with reminders to take medicines and a "panic button" for direct connection with the call centre (or telephone 112). Snezhana fortunately has not had to use this button.



## **3.12** Domain 1: Northern Ireland

## 3.12.1 Description of the health and social problem

In Northern Ireland, the BeyondSilos evaluation will focus on those patients identified by selected GP practices via a regional risk stratification process (already completed for purposes other than BeyondSilos) for whom a Share Care Summary (SCS) will be implemented. These high risk patients have chronic conditions and co/multi-morbidities. Those selected for the evaluation also have a social need and are in receipt of some form of social care.

Main health problems include (but may not be limited to) a primary diagnosis of:

- Congestive Heart Failure (CHF): I20-I25.
- Chronic obstructive pulmonary disorder (COPD): J40-J44.
- Diabetes Type 1 or Type 2: E10-E14.

The symptoms, natural course, possible consequences and the burden of disease for the patients are described in sections 3.3 and 3.4.

These elderly patients with long term conditions are very often frail, and will have a corresponding requirement for social care provision. Frequently they may have reduced mobility, a high risk of falling, and be confined to their home due to exacerbations in their health conditions. Personal and home help care, day care activities, and respite care, are some examples of services available. Frequently they will be in receipt of a multi-disciplinary care package, and be receiving services from a range of different health and social care professionals. The GP will retain the main responsibility for their care provision, but will refer them to other professionals as required.

## 3.12.2 Quantification of the burden of disease / health problem and social problem

The 2011 Northern Ireland census<sup>31</sup> indicates that there were 251,969 people ages 65 years and over in Northern Ireland; of these, 145,829 (57.88%) said that their day to day activities were limited by a long-term health problem or disability, while 34% (over 85,000) said that their activity was limited a lot.

The Information Analysis Directorate (IAD) of the Department of Health, Social Services and Public Safety<sup>32</sup> produces statistics on Community Care for Adults in Northern Ireland. The latest report published on 29<sup>th</sup> October 2015 gives the figures for the 2014/15 year. During this time there were 30,108 face-to-face contacts between a person or their carer(s) and a social worker or other member of statutory social services staff; of these persons, 11,861 (39%) were aged 65 years and over. Another IAD report indicates that in 2014 20,411 people aged 65 and over were in receipt of domiciliary care services. Domiciliary care is defined as the range of services put in place to support an individual in their own home.

An analysis of all deaths in Northern Ireland in  $2010-12^{33}$  indicates that circulatory diseases accounted for 29% of all deaths (12,428) and respiratory diseases accounted for 13% (5,832). Both COPD and CHF are regarded as amenable to or preventable by treatment (for ages 0 – 74 years). Diabetes Mellitus (DM) was identified as the underlying cause of 574 deaths in 2010-12 (c1.5%); DM is regarded as amenable or preventable for ages 0 – 49 years.

<sup>&</sup>lt;sup>31</sup> <u>http://www.nisra.gov.uk/census/2011</u>

<sup>&</sup>lt;sup>32</sup> www.dhsspsni.gov.uk/statistics

<sup>&</sup>lt;sup>33</sup> <u>https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/hscims-life-expectancy-decomposition-2015.pdf</u>



## 3.12.3 Management of the health and social problems

The patients selected for the Shared Care Summary part of the BeyondSilos project will be identified by the GP who is looking after their health. In the NIECR (Northern Ireland electronic care record) the GP will be able to see details of any contacts with an acute hospital (e.g. ED visits, inpatient and out-patient episodes), most laboratory results, and radiology images and reports. The GP record in their own system if they have made any referrals to community or social care services, but have no detail of the subsequent contact and outcomes. Community and social care staff input details of patient contacts, treatment and outcomes into a number of systems, some of which integrate with the NIECR. Care pathways followed by healthcare professionals may be as agreed at a Trust or Regional level, depending on the condition being treated.

Social assistance is dependent on an individual's assessed need, so it is not possible to state definitively what will be required for any particular health condition. In general, frail elderly people receive domiciliary services and possibly telecare for risk mitigation.

Even where people are under the care of a multi-disciplinary integrated team, the issues with multiple information systems and access problems exist in the current situation; there is no shared summary that all care providers can access to get an overall view of the care being provided to any single person.

Whilst some people may be in receipt of care services provided by non-statutory bodies such as those in the voluntary or commercial sector, and there is also a high proportion of family carers, these actors are excluded from the BeyondSilos Shared Care Summary project as none of them have access to the NIECR at the present.

To give a clear overview of the foreseen improvements of interaction between actors/sectors after the new BeyondSilos service has been introduced in Northern Ireland, Table 10 shows the current interaction between sectors (usual care) and the foreseen interaction between sectors (new care) after BeyondSilos has been introduced. Any improvements from "usual care" to "new care" have been highlighted and underlined in the table. The definition of the different levels is provided in section 3.5 above.

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	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Health services		•		•	•	•
Usual care	Medium: GPs, community nursing, allied health professionals, ED, acute inpatient and out- patient; some information available in NIECR. Multiple systems in use by different professionals. No single summary view available.	Medium: Referrals by GPs, other HCPs and self-referral. HCPs have no sight of SCP systems. Paper based and time consuming information flows.	Low: There may be some contact between statutory health professionals and third sector organisations which provide some level of service at a local level.	Low: There may be some interaction at a local level.	High: HCP view of CR info is fairly narrow and profession centric. None or limited view of other HCP/SCP information about CR.	Medium: Amount of interaction with family / entourage will vary from case to case.
New care	High: Access to SCS: all professionals can view the same information.	High: Access to SCS: all professionals can view the same information.	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.	Added Value: Access to SCS giving fuller information should lead to better clinical decisions being made about the CR and a better experience for the CR.	Added Value: Whilst family / entourage will have no access to NIECR/SCS, improved care to CR will impact on them.

Table 10: Northern Ireland: Interactions and integration within and between sectors (comparison between usual care at start vs new care at mid-term)



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Social services						
Usual care	Medium: Referrals by GPs, other HCPs and self-referral. SCPs have no sight of HCP systems. Paper based and time consuming information flows.	Medium: SCPs can share information in social care system with appropriate access controls (used mostly for team working to cover absence).	Low: There may be some contact between statutory social care professionals and third sector organisations which provide some level of service at a local level.	Low: There is some interaction at a local level, e.g. between Care Manager and private residential and nursing homes or private domiciliary care providers.	High: CR tends to interact with one named SCP only.	Medium: Amount of interaction with family / entourage will vary from case to case.
New care	No Changes: <u>Added Value:</u> Access to SCS; all professionals can view the same information.	High: Access to SCS; all professionals can view the same information.	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.	Added Value: Access to SCS giving fuller information should lead to better decisions being made about the CR and a better experience for the CR.	High: Whilst family / entourage will have no access to NIECR/SCS, improved care to CR will impact on them.
Third sector	1	1	1	1	1	1
Usual Care	Low: There may be formal interaction at a local level.	Low: There may be formal interaction at a local level.	None: Unaware of formal interactions between different organisations.	None: Unaware of formal interactions between different organisations.	Medium: Will vary from CR to CR; a large number will have no interaction at all; service and locality dependent.	Medium: Amount of interaction with family / entourage will vary from case to case.



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
New care	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.
Usual care	Low: There may be some interaction at a local level	Low: There will be some interaction at a local level, e.g. between Care Manager and private residential and nursing homes or private domiciliary care providers.	None: Unaware of formal interactions between different organisations	None: Unaware of formal interactions between different organisations	Medium: Will vary from CR to CR; a large number will have no interaction at all; service and locality dependent	Medium: Amount of interaction with family / entourage will vary from case to case.
New care	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Person- care rec	pient					
Usual care	High: CR moves between HCPs; frequent repetition of personal information. Possibility for repetition of tests as information not easily accessible. Delays in treatment due to lack of information.	High: SCP will have very limited view of health information.	Medium: Will vary from CR to CR; a large number will have no interaction at all; service and locality dependent	Medium: Will vary from CR to CR; a large number will have no interaction at all; service and locality dependent		
New care	Added Value: Access to SCS giving fuller information should lead to better clinical decisions being made about the CR and a better experience for the CR	Added Value: Access to SCS giving fuller information should lead to better decisions being made about the CR and a better experience for the CR	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Other providers currently have no access to NIECR, therefore no view of SCS.		



	Health services	Social services	Third sector	Other providers	Person- care recipient	Family –entourage
Family –entoura	ge					
Usual care	Medium: Amount of interaction with family / entourage will vary from case to case.	Medium: Amount of interaction with family / entourage will vary from case to case.	Medium: Amount of interaction with family / entourage will vary from case to case.	Medium: Amount of interaction with family / entourage will vary from case to case.		
New care	No Changes:	No Changes:	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.	No Changes: Third sector currently have no access to NIECR, therefore no view of SCS.		



# **3.12.4** The ICT solution supporting integrated care (including technical characteristics of the service)

A full description of the ICT solution can be found in deliverables D3.2 BeyondSilos Service specification and D4.2 BeyondSilos Prototype system.

The BeyondSilos pilot in Northern Ireland expands upon the successful Northern Ireland Electronic Care Record (NIECR) to increase availability of information about patients and clients to health and social care professionals who are planning for and providing them with care. There are three streams of work involved in the pilot:

- Integrate the regional Remote Telemonitoring service with the NIECR.
- Integrate data captured by the electronic Northern Ireland Single Assessment Tool (eNISAT) with the NIECR.
- Design and set-up a Share Care Summary (SCS) within the NIECR to pull together and display information to enable health and social care providers to see information relevant to each individual patient thereby facilitating better clinical decision making.

The Shared Care Summary (SCS) will sit within the NIECR. Information will either be pre-populated from elsewhere within the NIECR, or will be input and updated by the relevant member of the multidisciplinary team caring for the patient. The solution will provide for integrated care by enabling all care providers to see the same information, secure in the knowledge that it is accurate and up-to-date.

The SCS will be viewable by all health and social care providers with access to the NIECR who have obtained verbal consent from the patient to view their data. It is not available outside the statutory Health and Social Care service at this time (i.e. those with no access to NIECR).

The Northern Ireland Electronic Care Record (NIECR) brings together key information from health and social care records from throughout Northern Ireland in a single, secure computer system in order to provide better, safer, faster care. Access to NIECR was made available to authorised Health and Social Care (HSC) staff and GPs in Northern Ireland from July 2013.

## **3.12.5** Requirements for use of the ICT solution

As the SCS is being built into the NIECR it will be accessible to all users of the NIECR using their existing devices. No specific training will be required other than the general NIECR training to any new users of that system.

## **3.12.6 Case description**

In effect the only difference between the two pathways in Northern Ireland is the length of time the person is on them.

The cohort of evaluation patients are all on the long-term pathway, but a significant number may have periods of hospitalisation.

#### Use Case:

Betty Jones is an 84 year old lady who is a patient at the Grove medical practice in Armagh. Betty has a past medical history of CHF and COPD, and has chronic pain due to osteoporosis.

Betty has intermittent increases in low back pain, managed with short-acting morphine; her occasional CHF exacerbations are managed at home with diuretics.



From the ECR you can see that over the last few months, Betty has suffered repeated hospitalisation and functional decline with a corresponding decrease in her overall sense of satisfaction with her life. Her CHF is currently managed at home with diuretics, and she is under the care of a specialist respiratory nurse for her COPD. In November, Betty had minor trauma caused by sitting down abruptly on the commode. This resulted in excruciating low back pain the following day. She was hospitalised for pain control, but no new fractures were found. She was discharged to rehabilitation, but wants to return home.

Betty's GP sets up a Shared Care Summary for her in the NIECR. This is auto-populated with her demographic information and medical history. Her Heart Failure and Respiratory nurses are alerted that a SCS is in place.

Betty's GP refers her to Social Services to assess her needs to enable her to return home.

Social worker completes an eNISAT assessment for Betty; this is integrated with the NIECR, and the plan is fed to the SCS detailing the care package that is being put into place.

After Betty returns home, her Heart Failure and Respiratory nurses resume their care plans and update the nursing system; this feeds into the NIECR and updates the SCS.



## 4 Domain 2 and 3: Safety, clinical and social effectiveness

Information on domain 2 and 3 of the MAST model concerning the safety, clinical and social effectiveness of the ICT application will be included in the updated version of the deliverable D6.2 Interim Evaluation Report by the end of January 2016. In this present chapter, the framework of the expected data collection can be viewed.

## 4.1 Guideline for reporting

Since most of the pilot sites have only just finished recruiting all participants in the BeyondSilos project, the reporting from Domain 2&3 will focus on:

- Care recipients.
- Objectives.
- Care recipient flow and recruitment.
- Baseline characteristics.

#### 4.1.1 Care recipients

In this section, specific information about the eligibility criteria for the patient, and the settings and the locations where the data are collected, will be described for each pilot.

The eligibility criteria include information on disease, social needs, age limits, restrictions on comorbidities, etc.

#### 4.1.2 Objectives

All pilot sites will state their local objectives of the BeyondSilos service.

## 4.1.3 Care recipient flow and recruitment

A flow chart of the care recipients' path throughout the BeyondSilos will be presented for each pilot site. The figure will provide for all care recipients:

- Tested for eligibility.
- Found eligible.
- Included according to group.
- Provided with service according to group.
- Included in baseline analyses according to group.

The pilot sites will describe all elements of the figure in detail including the reasons for non-participation, if possible, since this could affect the external validity (validity of generalised results). Pilot sites that do not have all the information required in the flowchart will indicate missing information with a question mark (?) in the relevant box. If possible, the number of people assessed for eligibility will also be reported. This can be difficult for some pilots, but it is very important for the assessment of the external validity of the study because the numbers indicate whether the care recipients are likely to be representative of all eligible possible users.

In relation to the description of the participant flow, it will also be noted at which date the recruitment was being carried out.



The chart below is based on the CONSORT statement<sup>34</sup>. Please note that the flowchart has been adjusted, since the CONSORT statement is a guideline aimed at randomised controlled trials. An explanation of what each box can be found after the chart.



Please note: n is the <u>n</u>umber of people.

Figure 6: Template for flowchart of participants' paths through the BeyondSilos project

**Assessed for eligibility**: The number of people that were considered as subjects for inclusion in the study. This number should include the total number of people, disregarding whether they were included or not.

**Excluded**: This is the number of people that ended up NOT being included into the study. It is further specified into categories describing the cause of each individual to not be included. The pre-specified categories are:

<sup>&</sup>lt;sup>34</sup> Zwarenstein M, <u>Treweek S, Gagnier JJ, Altman DG, Tunis S, Haynes B, Oxman AD, Moher D</u>; CONSORT group; <u>Pragmatic Trials in Healthcare (Practihc) group</u>. Improving the reporting of pragmatic trials: an extension of the CONSORT statement. <u>BMJ</u>. 2008 Nov 11;337:a2390



- 1) Patient refuses the use of devices.
- 2) Felt overwhelmed with the amount of information they needed to provide.
- 3) Did not want to participate for health reasons.
- 4) Did not find the subject of the study relevant for their own situation.
- 5) Refuses participation in studies in general.
- 6) Did not believe that data protection was ensured.
- 7) Did not want to explain their decision.
- 8) Other reason. This category gives the opportunity to give other reasons. These reasons should be specified. So, if one care recipient gives the reason "I have not internet connection", that should be stated as an option, and each number of care recipients that give that

Excluded is a highly

important category, for transferability purposes. So please read the section carefully, and contact WP8 lead if you have any questions

reason should be counted and registered as such. So, this is the field to note the possible, and highly important, reasons for declining that might not be related to the criteria for inclusion, e.g. "Cannot afford equipment", "No equipment available", etc.

Please note that in some settings it may be illegal to require care recipients to explain why they did not want to participate. So, if you are allowed to ask the question, feel free to do so. It can definitely provide interesting information, but it is not a mandatory measure.

**Included**: Is the number of care recipients that were chosen for inclusion in the BeyondSilos service, and who entered the study as care recipient. So, the numbers should add up (Excluded + Included = Assessed).

**Allocation**: Describes the way in which the total sample was divided into the two groups of intervention and control. It is not described within the figure, but is clearly described in the "Methods" section (see below).

Allocation to BeyondSilos service: Includes the number of care recipients that were allocated to (=put into) the BeyondSilos service group. In practice, this means the number of care recipients that were meant to receive the BeyondSilos service. As a subsection, it needs to be specified how many care recipients did receive the BeyondSilos service. This is necessary due to the fact that reality does not always reflect the plans. If no care recipients ended up NOT receiving the BeyondSilos service, the number should be equal to the overall category of "Allocated to BeyondSilos service". The second subgroup "Did not receive allocated BeyondSilos service", also called "drop-off", is the number of care recipients that did not receive the service although they should have. There can be multiple reasons for this, and it is important to register the reasons so that if the causes are practical, these can be resolved at a later stage. Sometimes care recipients do not receive the service because they die in the meantime. Sometimes they do not receive the service because something went wrong with the message that they should receive it. Sometimes other things cause the care recipients to not receive the intended service. If this does not happen at the local deployment site, the category should include "n=0". Please note that the numbers should add up (Received allocated BeyondSilos service + did not receive allocated BeyondSilos service = Allocation to BeyondSilos service).

Allocation to usual service: Includes the number of care recipients that were allocated to (= put into) the usual service group. It needs to be specified as a subsection, how many of the care recipients did receive the usual service intervention and how many that did not receive the usual service intervention. The purposes are similar to those of the category above "Allocated to BeyondSilos service".

**Follow-up**: This category does not need a description within the figure. Instead, it should be described within the "Methods" section, how and when the care recipients were followed up.



Please note that if you have decided to have multiple follow-ups for each group (i.e. at eight weeks and at eight months), the follow-up part of the figure should be repeated for each additional follow up, since it is likely that with time, more care recipients leave the study. It might be a valuable finding, if there are trends in the pattern of leaving the study, so one follow-up section of the figure is necessary for one follow-up in real life.

Lost to follow up intervention group: Within the intervention group it might happen that some care recipients are lost during the follow-up, and that they cannot be identified, so their follow-up data are unavailable for analysis. This can be caused by people moving to other geographic areas or other reasons. Please keep a record of the reasons that some people are lost to follow-up. As a sub-group, some people are lost to follow-up because they choose to withdraw their informed consent. If it is legal within your setting, please keep a record of the reasons for wanting to leave the study. If it is not legal, please just keep note of how many care recipients decide to leave the study.

**Lost to follow up control group**: This is similar to the "Lost to follow up intervention group", except that it concerns care recipients within the control group.

**Analysis**: This section does not need to be explained within the figure. Instead, it should be clearly described within the "Methods" section (see below).

**Analysis intervention group**: This describes the number of care recipients that were included in the final analyses. If some were excluded, it should be stated how many, and why, in the sub-group "Excluded from analysis intervention group". It might be that there is a rule that only care recipients with > 50% of observations available are included in analyses, or there might be other reasons that a few individuals are excluded from the analyses, e.g. another severe disease was identified during the study period.

**Analysis control group**: As for the "Analysis intervention group", it is important to take note of any care recipients that were excluded from the analyses, including the reasons for this decision. Reasons should be similar for both intervention and control groups.

## 4.1.4 Baseline characteristics

Table 11 shows all the mandatory baseline variables that each pilot site has been collecting, according to group distribution and the p-value for the difference.

When calculating, the type and distribution of each variable determines how it should be presented. **Numerical** variables, also known as "counts" (values that have an absolute 0, and have equal distance between 0 and 1 as for 1 and 2) should be presented with a **mean** (the average value) and **standard deviation** (SD) (the average difference between the mean value and the observations). The only exception is the variable "Sample size" which needs to be presented as a **categorical** variable (a variable where you cannot assume that there is a rank between the categories, e.g. gender and marital status). These variables are presented with the **absolute value** (i.e. how many) and a **percentage** (the percentage).

Variable	Measurement	Intervention	Control	Difference (p)
1	Sample size (n (%))			
2	Age (mean (SD))			
3	Gender, male (n (%))			
4	Marital status (n (%))			
4.1	Never married			
4.2	Currently married			
4.3	Separated			

Table 11:	Template	for ta	ble of	baseline	characteristics
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Variable	Measurement	Intervention	Control	Difference (p)
4.4	Divorced			
4.5	Widowed			
4.6	Cohabitating			
4.7	Missing answer			
5	Education (n (%))			
5.1	Less than primary school			
5.2	Primary school			
5.3	Secondary school			
5.4	High school			
5.5	College/University			
5.6	Post graduate degree			
5.7	Missing answer			
6	Longest held occupation (n (%))			
6.1	Manual			
6.2	Non manual			
6.3	Unemployed (able to work)			
6.4	Unemployed (unable to work)			
6.5	Homemaker			
6.6	Missing answer			
7	Housing tenure (n (%))			
7.1	Owners			
7.2	Renters			
7.3	Missing answer			
8	People older than 18 living in			
	household in addition to the			
	care recipient (mean (SD))			
9	Smoking status (n (%))			
9.1	Never			
9.2	former			
9.3	current smoker			
9.4	e-cigarette			
9.5	Other			
9.6	Missing answer			
10	Alcohol (n (%))			
10.1	None			
10.2	Less than 1/week			
10.3	1-7/week			
10.4	8-14/Week			
10.5	15-21/week			
10.6	More than 21/week			
10.7	Missing answer			
	PC USE ( <i>n</i> (%))			
12	IVIODIIE phone use ( <i>n</i> (%))			
13	Height in cm ( <i>mean</i> (SD))			
14	Weight in kg (mean (SD))			
		Co-morbidity	/	



Variable	Measurement	In	tervention	Control	Difference (p)
15	Primary disease (n (%))				
15.1	Primary disease CHF				
15.2	Primary disease COPD				
15.3	Primary disease DIABETES				
16	Secondary disease (n (%))				
16.1	Secondary disease CHF				
16.2	Secondary disease COPD				
16.3	Secondary disease DIABETES				
17	Social support (n (%))				
17.1	Technical support				
17.2	Logistic support				
17.3	Personal support				
17.4	Loan services support				

Tests	Measurement	Intervention Baseline	Control Baseline	Difference (p)
Barthel index (mean (SD))	Score			
Instrumental activity of daily living (IADL) <i>(mean (SD))</i>	Score			
Geriatric Depression Scale (GDS) (mean (SD))	Score			

## 4.2 Overall comparison across pilot sites

This section provides an overview across all pilot sites. Details at site level are provided in sections 4.3 to 4.9.

## 4.2.1 Care recipients

#### Inclusion criteria for end users:

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

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



#### Exclusion criteria for end users:

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

#### 4.2.2 Aim and objectives

#### Aim

The overall aim of the BeyondSilos project is to optimise the care continuum for elderly care recipients with multiple co-morbidities and social needs by providing ICT supported integrated care.

#### Objectives

To examine the effect of introducing ICT supported integrated care for care recipients with multiple comorbidities and social needs by comparing:

- Numbers and types of contacts with the health and social care sector for care recipients receiving the new BeyondSilos care compared with persons receiving usual care.
- Differences in mortality rates for care recipients receiving the new BeyondSilos treatment compared with persons receiving usual care.
- Changes in activities of daily living (Barthel & IADL scales) and mood (Geriatric Depression Scale) between care recipients receiving the new BeyondSilos care compared with persons receiving usual care.
- Examine the economic and organisational impact of the new integrated service and the acceptability by care recipients and professionals.



## 4.2.3 End-user flow and recruitment



#### Flow-chart description

Out of the 986 care recipients assessed for eligibility between the pilot sites, 446 were invited to participate in the BeyondSilos (BS) project, and 540 were excluded. Reasons for exclusion were: Did not meet the inclusion criteria (238), declined to participate (173), and exclusion for other reasons (129) (having a high probability of being lost to follow-up, or drop-off, or declining to participate after new BeyondSilos care had been explained to them).

Of the 446 care recipients included in the BS project, 236 were allocated to the BS service, and 210 to usual care. Among the 236 allocated to BS service, 19 did not receive the BS service. Most often, the reason for these drop-offs were that: either the caregiver or a relative did not want their relatives to



participate; or they did not have a fixed telephone line. One pilot site reported eight deaths (lost to follow-up) in the BS intervention group after they had been assigned to the BS service; these care recipients are therefore included in the baseline analyses.

Among the 210 care recipients allocated to usual care, two were reported lost to follow-up (one deceased, and one moved to nursing home). One pilot site decided to "keep" 17 participants from the usual care group in reserve, waiting to be paired with further participants in the intervention group; these have therefore not been included in the baseline analysis so far.

To sum up, 217 participants have been allocated to the new BeyondSilos service and included in the baseline analysis, and 193 participants have been allocated to usual care and included in the baseline analysis.

## 4.2.4 Baseline characteristics

In BeyondSilos, all pilot sites have a common aim, which is to optimise the care continuum for elderly care recipients with multiple co-morbidities and social needs by providing ICT supported integrated care. However, the new BeyondSilos service being introduced differs across sites. In addition, cultural differences in care and lifestyles of care recipients may occur between the different pilot sites. These are factors which all have to be taken into consideration in the final overall statistically analysis across pilot sites.

In this interim evaluation report, we show overall comparisons of the distribution of selected variables. The report does not show any comparisons between care groups, since baseline data is available for only 29% of the care recipients planned to be enrolled; not all pilot sites have been able to contribute baseline data yet. The following tables are a "snapshot" of the data collected as at mid January 2016, and should not be used for interpretation or assumptions of associations.

The tables combine baseline results from the following sites: Kinzigtal, Sofia, Campania (only new care group), Badalona and Valencia.

	Planned			Current status N (%of planned)		
Pilot site	New Care	Usual Care	Total	New Care	Usual Care	Total
Northern Ireland	210	210	420	0 (0)	0 (0)	0 (0)
Amadora	150	150	<b>300</b> (150 care recipients before and after)	0 (0)	0 (0)	0 (0)
Kinzigtal	50	50	100	30 (60)	53 (106)	83 (83)
Sofia	50	50	100	50 (100)	50 (100)	100 (100)
Campania	50	50	100	48 (96)	0 (0)	48 (48)
Badalona	100	100	200	49 (49)	50 (50)	99 (50)
Valencia	100	100	200	40 (40)	40 (40)	80 (40)
Total	710	710	1420	217 (31)	193 (27)	410 (29)

Table 12: Overall distribution of care recipients included in the baseline tables by pilot site and care group

Table 12 shows the numbers of participants that have been included in the baseline tables produced by the pilot sites. Overall the pilot sites plan to include 1420 participants in the evaluation of the BeyondSilos project, 710 receiving the new BS service, and 710 receiving usual care for comparison.



By mid January 2016 the pilot sites had collected baseline information for 31% of participants receiving the new BS service, and 27% of those receiving usual care. In total, the pilot sites had collected baseline information for 29% of the planned care participants.

**Error! Not a valid bookmark self-reference.** shows that the overall mean age for both the new BS care group and the usual care group is 81 years. Overall, 36% of the participants with baseline data are males. 33% of the new BS care group are males compared with 40% in the usual care group.

Table 13: Overall distribution of mean age and gender by care group

Variable	New care, N = 217	Usual care, N = 193	Total, N = 410
Age, mean	81	81	
Gender, male (N, %)	72 (33%)	77 (40%)	149 (36%)

It seems that more participants in the usual care group suffer from CHF than in the new BS care group and that participants from the new BS care group suffer from diabetes more often.

This distribution can however change when the rest of the participants have been enrolled and included in the baseline tables.

Table 14 shows that out of the 410 participants included in the BS project, 55% have CHF as a primary condition, 23% have diabetes, 17% COPD, 3% stroke and 1% have hip fracture as their main condition.

It seems that more participants in the usual care group suffer from CHF than in the new BS care group and that participants from the new BS care group suffer from diabetes more often.

This distribution can however change when the rest of the participants have been enrolled and included in the baseline tables.

Variable	New care, N = 217	Usual care, N = 193	Total, N = 410
Primary disease, CHF	99 (45)	125 (65)	224 (55)
Primary disease, stroke	11 (5)	0 (0)	11 (3)
Primary disease, COPD	37 (17)	31 (16)	68 (17)
Primary disease, diabetes	67 (31)	28 (15)	95 (23)
Primary disease, hip fracture	4 (2)	2 (1)	6 (1)

Table 14: Overall distribution of Primary diseases by care group, N (%)

Table 15 shows that out of the 410 participants included in the BS project, 30% have CHF as a secondary condition, 18% have COPD, 21% diabetes, and 1% have hip fracture.

It seems that more participants receiving the new BS care suffer from CHF and COPD as their second condition compared to participants in the usual care group.

Variable	New care, N = 217	Usual care, N = 193	Total, N = 410
Secondary disease, CHF	76 (35)	48 (25)	124 (30)
Secondary disease, stroke	0 (0)	0 (0)	0 (0)
Secondary disease, COPD	49 (22)	23 (12)	72 (18)
Secondary disease, diabetes	45 (21)	41 (21)	86 (21)
Secondary disease, hip fracture	2 (1)	0 (0)	2 (1)

Table 15: Overall distribution of secondary diseases by care group, N (%)



**Error! Not a valid bookmark self-reference.** shows the overall distribution of social support for participants included in the BS project. Out of these 362 participants, 27% receive technical support, 57% logistic support, 41% personal support and 35% receive loan service support.

It seems that more participants in the usual care group receive logistic support and personal support than in the new BS care group, and that participants from the new BS care group receive technical support more often than those in the usual care group.

This distribution can however easily change when the rest of the participants have been enrolled and included in the baseline tables

Variable	New care, N = 169 (24)	Usual care, N = 193 (25)	Total, N = 362 (100)
Technical support	49 (29)	47 (24)	96 (27)
Logistic support	85 (50)	120 (63)	205 (57)
Personal support	67 (39)	83 (43)	150 (41)
Loan service support	58 (34)	67 (35)	125 (35)

Table 16: Overall distribution of Social support by care groups, N (%)\*

\* Campania have not collected data on social support yet and are therefore not included in the table. Therefore, only a total of 362 care recipients are included in the distributions.

## 4.3 Domain 2&3: Badalona

## 4.3.1 Care recipients

In BSA, two profiles of users have been included in the framework of BeyondSilos.

**Short-term pathway:** The short term pathway includes care recipients (CRs) requiring specific health and social intervention, for a limited time period of 6-8 weeks. Even though it was also possible to be included in the short term pathway after a life event leading to social care (e.g. partner's death and a new situation of isolation), all the individuals so far have been included after an acute medical event. All CRs enrolled in the short term pathway fulfilled the inclusion criteria of age >65 years-old with CHF, COPD or diabetes as a primary diseases, and in all cases were recruited after admission to hospital. However, the new health event was not necessarily related to the primary disease, as we found this intervention particularly useful also after stroke or surgery (traumatological fracture). Indeed, these situations of increased frailty mostly require stays in a rehabilitation centre, but sometimes an early discharge is possible if social and recovery support can be organised at home. So CRs with stroke and hip fractures were included if they otherwise met the other inclusion criteria. The CRs were enrolled either as a case in the intervention group or as a control according to dates of discharge from hospital. If, after 8 weeks of intervention, the CR still required medical or social help, he/she was enrolled in the long term programme.

**Long-term pathway:** Individuals >65 years-old suffering from any of the illness reported above as an inclusion criteria, including previous stroke, and requiring continuous health and social support at home. They were enrolled either by physician, case managers (nurses) or by social workers with the condition of living within the BSA's influence area. Obviously, this profile of CRs usually presents other associated chronic diseases making their management even more complex. Their social needs may range from a situation of isolation to a severe dependency. Recruitment was obtained from our general database, providing lists of subjects fulfilling the inclusion criteria in every primary care area. The selection as an intervention case or control by the responsible team in each area was expected to be done alternatively from their respective lists.



Below we present the baseline data of the first iteration of care recipients included in both profiles, corresponding to the first eight months of development of BeyondSilos in our institution. A second iteration is already ongoing.

#### 4.3.2 Aims and objectives

#### Aims

To improve our integrated care providing the tools (shared electronic health and social care platform) for a better coordination between the agents involved.

To optimise the care continuum between different levels of assistance by means of the improvement of shared electronic information and the implementation of medical telemonitoring.

#### Objective

To examine the effect of a shared electronic care platform and medical telemonitoring on the integrated care of the individuals included.

The following analyses will be done separately for CRs in the short-term and long-term pathway:

- Comparing differences in numbers of contacts (nurse, GP, specialist physician, social worker, volunteer) and their type (phone calls, home visits, outpatient visits, emergency department, hospital admissions) with the healthcare and social care system, between CRs receiving the new BeyondSilos service and CRs receiving usual care.
- Comparing differences in mortality rates between CRs receiving the new BeyondSilos service and CRs receiving usual care.
- Comparing changes in activity of daily living (Barthel & IADL scales) and mood (Geriatric Depression Scale) between CRs receiving the new BeyondSilos service and CRs receiving usual care (in our pilot site a particular challenge in short-term interventions).
- Comparing CRs' final satisfaction between those in the new BeyondSilos service and CRs receiving usual care.
- Examine the economic and organisational impact of the new integrated service and the acceptability by CRs and professionals.



#### 4.3.3 End-user flow and recruitment

#### Short-term pathway flowchart



#### Figure 7: Badalona: Flowchart of participants' paths - short term pathway

In the first iteration of inclusion in the short-term pathway, we assessed 23 individuals admitted to our hospital, all of them fulfilling the inclusion criteria. Three of them declined to participate, two in the intervention group arguing they felt overwhelmed by the use of devices, and one in the control group who did not want to explain his reason(s). All the participants in both groups (ten in each) were followed in parallel during 6-8 weeks, without drop-offs. Baseline data were available for all of them for comparison between groups.



#### Long-term pathway flowchart



Figure 8: Badalona: Flowchart of participants' paths - long term pathway

In the first iteration of inclusion in the long-term pathway, we assessed 117 people according the register from our database. However, a further review of their medical records identified two individuals who were not eligible because they did not strictly fulfil the inclusion criteria. 34 declined to participate when they were asked by their usual case manager nurse. From the remaining 81 people, we included 41 in the intervention group, because we needed to replace one whose family had signed the informed consent but died prematurely before the telemonitoring was deployed at home; 40 controls were included and followed in parallel. No one in either group withdrew their consent, moved geographically, or had any other reason that resulted in loss to follow-up. However, at the time of reporting the baseline statistical analyses below, data in the intervention group were available for only 39 participants because there was one missing record in the database.



## 4.3.4 Baseline characteristics

## Short-term

Variable	Measurement	Intervention	Control	Difference (p)
1	Sample size (n (%))	10 (20)	10 (20)	
2	Age (mean (SD))	83.7 ± 4.809	86.3 ± 5.832	0.854
3	Gender (male) <i>(n (%))</i>	1 (10)	4 (40)	0.121
4	Marital status <i>(n (%))</i>			0.675
4.1	Never married	1 (10)	1 (10)	
4.2	Currently married	3 (30)	2 (20)	
4.3	Separated	0 (0)	0 (0)	
4.4	Divorced	0 (0)	0 (0)	
4.5	Widowed	5 (50)	7 (70)	
4.6	Cohabitating	1 (10)	0 (0)	
4.7	Missing answer	0 (0)	0 (0)	
5	Education (n (%))			0.807
5.1	Less than primary school	3 (30)	5 (50)	
5.2	Primary school	4 (40)	3 (30)	
5.3	Secondary school	1 (10)	1 (10)	
5.4	High school	2 (20)	1 (10)	
5.5	College/University	0 (0)	0 (0)	
5.6	Post graduate degree	0 (0)	0 (0)	
5.7	Missing answer	0 (0)	0 (0)	
6	Longest held occupation (n (%))			0.306
6.1	Manual	2 (20)	5 (50)	
6.2	Non manual	2 (20)	1 (10)	
6.3	Unemployed (able to work)	0 (0)	0 (0)	
6.4	Unemployed (unable to work)	0 (0)	1 (10)	
6.5	Homemaker	6 (60)	3 (30)	
6.6	Missing answer	0 (0)	0 (0)	
7	Housing tenure (n (%))			0.807
7.1	Owners	5 (50)	9 (90%)	
7.2	Renters	1 (10)	1 (10%)	
7.3	Missing answer	4 (40)	0 (0%)	
8	People older than 18 living in household in addition to the care recipient (mean (SD))	0.9 ± 0.88	0.7 ± 0.48	0.535
9	Smoking status (n (%))			0.121
9.1	Never	8 (80)	6 (60)	
9.2	former	2 (20)	4 (40)	
9.3	current smoker	0 (0)	0 (0)	
9.4	e-cigarette	0 (0)	0 (0)	
9.5	Other	0 (0)	0 (0)	
9.6	Missing answer	0 (0)	0 (0)	

Table 17: Badalona: Table of baseline characteristics - short term pathway



Variable	Measurement	Intervention	Control	Difference (p)	
10	Alcohol (n (%))			0.308	
10.1	None	6 (60)	9 (90)		
10.2	Less than 1/week	1 (10)	0 (0)		
10.3	1-7/week	1 (10)	1 (10)		
10.4	8-14/week	2 (20)	0 (0)		
10.5	15-21/week	0 (0)	0 (0)		
10.6	More than 21/week	0 (0)	0 (0)		
10.7	Missing answer	0 (0)	0 (0)		
11	PC use ( <i>n (%))</i>	0 (0)	0 (0) Yes	1	
12	Mobile phone use	2 (20)	2 (20) Yes	1	
13	Height in cm (mean (SD))	154.9 ± 8.386	160.2 ± 7.361	0.563	
14	Weight in kg (mean (SD))	66.8 ± 10.239	65.9 ± 10.3	0.969	
	Co-morbidity				
15	Primary disease (n (%))				
15.1	Primary disease CHF	3 (30)	5 (50)	0.361	
15.2	Primary disease COPD	1 (10)	3 (30)	0.264	
15.3	Primary disease DIABETES	0 (0)	0 (0)	1	
	Primary disease FRACTURE	4 (40)	2 (20)	0.329	
	Primary disease STROKE	2 (20)	0 (0)	0.136	
16	Secondary disease (n (%))				
16.1	Secondary disease CHF	4 (40)	4 (40)	1	
16.2	Secondary disease COPD	2 (20)	1 (10)	0.531	
16.3	Secondary disease DIABETES	2 (20)	0 (0)	0.136	
17	Social support (n (%))				
17.1	Technical support	6 (60)	7 (70)	0.639	
17.2	Logistic support	5 (50)	8 (80)	0.160	
17.3	Personal support	4 (40)	5 (50)	0.653	
17.4	Loan services support	3 (30)	5 (50)	0.361	

Tests	Measurement	Intervention Baseline	Control Baseline	Difference (p)
Barthel index (mean (SD))	100	65.5 (19.784)	57.5 (31.645)	0.102
Instrumental activity of daily living (IADL) (mean (SD))	8	3.4 (2.71)	2.2 (2.53)	0.557
Geriatric Depression Scale (GDS) (mean (SD))	Score	4.4 (3.470)	6 (3.091)	0.833

<u>Comments</u>: Regarding the short-term users, both groups (intervention and control) were adequately balanced, except in gender. All but one in the intervention group were women, corresponding to the fact that nearly half (4/10) of cases were recruited after hip fracture; it is well known that osteoporosis is more frequent in older women. Two cases of stroke benefited from the intervention compared with none in the control group. No other significant differences were remarkable, including baseline status assessed by Barthel, IADL & GDS index.



## Long-term

Variable	Measurement	Intervention	Control	Difference (p)
1	Sample size (n (%))	39 (78)	40 (80%)	
2	Age (mean (SD))	84.5 ± 7.167	79.8 (7.8%)	0.151
3	Gender (male) <i>(n (%))</i>	10 (25%)	24 (60%)	0.005
4	Marital status (n (%))			0.166
4.1	Never married	1 (2.5%)	1 (2.5%)	
4.2	Currently married	12 (30%)	21 (52.5%)	
4.3	Separated	0 (0%)	1 (2.5%)	
4.4	Divorced	0 (0%)	1 (2.5%)	
4.5	Widowed	26 (65%)	16 (40%)	
4.6	Cohabitating	0 (0%)	0 (0%)	
4.7	Missing answer	0 (0%)	0 (0%)	
5	Education (n (%))			0.313
5.1	Less than primary school	21 (52.5%)	13 (32.5%)	
5.2	Primary school	12 (30%)	20 (50%)	
5.3	Secondary school	0 (0%)	2 (5%)	
5.4	High school	2 (5%)	2 (5%)	
5.5	College/University	1 (2.5%)	1 (2.5%)	
5.6	Post graduate degree	0 (0%)	0 (0%)	
5.7	Missing answer	3 (7.5%)	2 (5%)	
6	Longest held occupation (n (%))			<0.05
6.1	Manual	9 (22.5%)	32 (80%)	
6.2	Non manual	4 (10%)	5 (12.5%)	
6.3	Unemployed (able to work)	0 (0%)	0 (0%)	
6.4	Unemployed (unable to work)	0 (0%)	0 (0%)	
6.5	Homemaker	18 (45%)	3 (7.5%)	
6.6	Missing answer	8 (20%)	0 (0%)	
7	Housing tenure (n (%))			0.393
7.1	Owners	34 (85%)	32 (80%)	
7.2	Renters	3 (7.5%)	7 (17.5%)	
7.3	Missing answer	2 (5%)	1 (2.5%)	
8	People older than 18 living in household in addition to the care recipient (mean (SD))	2.51 ± 1.25	2.01 ± 0.80	0.07
9	Smoking status (n (%))			0.02
9.1	Never	30 (76.9%)	18 (45%)	
9.2	former	8 (20.5%)	20 (50%)	
9.3	current smoker	0 (0%)	2 (5%)	
9.4	e-cigarette	0 (0%)	0 (0%)	
9.5	Other	0 (0%)	0 (0%)	
9.6	Missing answer	1 (2.6%)	0 (0%)	
10	Alcohol <i>(n (%))</i>			0,04
10.1	None	37 (94.8%)	29 (72.5%)	

Table 18: Badalona: Table of baseline characteristics - long term pathway



Variable	Measurement	Intervention	Control	Difference (p)
10.2	Less than 1/week	1 (2.6%)	3 (7.5%)	
10.3	1-7/week	1 (2.6%)	8 (20%)	
10.4	8-14/week	0 (0%)	0 (0%)	
10.5	15-21/week	0 (0%)	0 (0%)	
10.6	More than 21/week	0 (0%)	0 (0%)	
10.7	Missing answer	0 (0%)	0 (0%)	
11	PC use (n (%))	1 (2.5%)	6 (15%)	0.09
12	Mobile phone use (n (%))	9 (22.5%)	27 (67.5%)	<0.05
13	Height in cm (mean (SD))	157.7 ± 9.811	163.9±10.7	0.441
14	Weight in kg (mean (SD))	71.5 ± 13.477	72.1±17.6	0.128
		Co-morbidity		
15	Primary disease (n (%))			
15.1	Primary disease CHF	11 (27.5%)	24 (60%)	0.01
15.2	Primary disease COPD	2 (5%)	14 (35%)	0.003
15.3	Primary disease DIABETES	9 (22.5%)	2 (5%)	0.04
	Primary disease STROKE	9 (22.5%)	0 (0%)	
16	Secondary disease (n (%))			
16.1	Secondary disease CHF	14 (35%)	9 (22.5%)	0.25
16.2	Secondary disease COPD	5 (12.5%)	5 (12.5%)	0.6
16.3	Secondary disease DIABETES	2 (5%)	10 (25%)	0.03
	Secondary disease HIP FRACTURE	2 (5%)	0 (0%)	
	(	Comorbidities (n (%)	)	
	Cerebral disease	23 (57.5%)	10 (25%)	0.006
	Dementia	17 (42.5%)	3 (7.5%)	0.001
	Charlson Index	7.913 ± 2.18	7.83 ± 2.02	0.99
17		Social support (n (%)	)	
17.1	Technical support	21 (52.5%)	16 (40%) Yes	0.282
17.2	Logistic support	21 (52.5%)	34 (85%)	0.006
17.3	Personal support	30 (75%)	10 (25%)	<0.05
17.4	Loan services support	29 (72.5%)	10 (25%)	<0.05

Tests	Measurement	Intervention Baseline	Control Baseline	Difference (p)
Barthel index (mean (SD))	100	40.38 (30.115)	80.5 (20.41)	0.001
Instrumental activity of daily living (IADL) (mean (SD))	8	1.15 (1.703)	3.75 (2.3)	0.01
Geriatric Depression Scale (GDS) (mean (SD))	Score	7.7 (3.204)	5,2 (3.2)	0.99

<u>Comments</u>: More women than men were included in the long term programme. However, the most significant difference was the worse baseline status in the intervention group compared with controls, reflected in Barthel, IADL and GDS scales. We have reviewed the reasons for such imbalance, and discovered a clear disproportion of CRs with previous cerebral disease and dementia in the intervention group. Nevertheless, when calculating the level of comorbidity (Charlson index), it was similar in both



groups. So we conclude that the intervention group presents so far a more frail profile. Although statistically not significant, the intervention group is five years older than controls. Other possible differences are less relevant in terms of the final validity of the study.

As a second iteration of inclusion was planned, we have undertaken measures to try to balance the intervention and control groups at the end of the study. In particular in the long-term pathway, a certain selection of some patients in the group to be included would be advised.

## 4.4 Domain 2&3: Valencia

#### 4.4.1 Care recipients

Care recipients in Valencia pilot site are patients included in the Case Management Care Plan of Health Department Valencia-La Fe. Among these patients, we selected those who met the inclusion criteria: elderly care recipients (65 years old or above) with primary diagnosis of CHF, COPD, diabetes or stroke with IADL and social needs.

#### 4.4.2 Aims and objectives

#### Aim:

To deploy an integrated care service supported by ICT tools for patients of Health Department Valencia La Fe followed in Case Management Programme. To increase the quality of care of complex chronic patients (patients with high risk of descompensation).

#### **Objectives:**

To examine the effect of introducing ICT tools into care management work routine for health and social care professionals, and to introduce a self-care management culture to patients and caregivers routinely using ICT devices to communicate with their health and social care professionals. This will be done by:

- Comparing differences in numbers and types of contacts with the healthcare and social care system between care recipients receiving the new BeyondSilos service and participants receiving the usual care.
- Comparing differences in clinical values between care recipients receiving the new BeyondSilos service and participants receiving the usual care.
- Comparing changes in activity of daily living between care recipients receiving the new BeyondSilos service and participants receiving the usual care.
- Examine the economic and organisational impact of the new integrated service and the acceptability by care recipients and professionals.



#### 4.4.3 End-user flow and recruitment



Figure 9: Valencia: Flowchart of participants' paths


#### Flow-chart description

Among 439 care recipients assessed for eligibility, we excluded 325. Of these, 149 subjects did not meet the inclusion criteria, 59 declined to participate at first phone contact, and 117 were excluded for other reasons, including a high probability of being lost to follow-up or drop-off (nurse criteria), declined to participate after intervention study explanation.

A total of 114 CRs were invited to participate in the BeyondSilos project in either the intervention or control group. Allocation was 1:1; 57 were allocated at BeyondSilos service and 57 were allocated to usual care. Among those 57 that were allocated to BeyondSilos service, 15 patients declined to participate once the nurse visited the home and explained the study; reasons of non participation were: caregiver or relative did not want their relatives to participate; or they did not have a fixed telephone line.

During the follow up period previous to baseline analysis, three care recipients from BeyondSilos allocation group decided not to continue in the study. One, because his daughter decided that her father was not sufficiently prepared to deal with technology, and two others thought that the tablet failed too often and was not easy to use.

At baseline analysis, we have 40 CRs allocated to the intervention and 40 allocated to usual care. We have "kept" 17 usual care users in reserve, waiting to be paired with further participants in the intervention group.

## 4.4.4 Valencia: Baseline characteristics

Variable	Measurement	Intervention	Control	Difference (p)
1	Sample size (n (%))	41 (51)	39 (49)	
2	Age (mean (SD))	79,7 (8,7)	78,9 (7,5)	
3	Gender (male) <i>(n (%))</i>	25 (61)	20 (51)	
4	Marital status (n (%))			
4.1	Never married	1 (2)	1 (3)	
4.2	Currently married	27 (66)	25 (64)	
4.3	Separated	0 (0)	1 (3)	
4.4	Divorced	1 (2)	0 (0)	
4.5	Widowed	11 (27)	12 (31)	
4.6	Cohabitating	0 (0)	0 (0)	
4.7	Missing answer	1 (2)	0 (0)	
5	Education (n (%))			
5.1	Less than primary school	18 (44)	23 (59)	
5.2	Primary school	14 (34)	13 (33)	
5.3	Secondary school	3 (7)	2(5)	
5.4	High school	2 (5)	0 (0)	
5.5	College/University	2 (5)	0 (0)	
5.6	Post graduate degree	0 (0)	0 (0)	
5.7	Missing answer	2 (5)	1 (3)	
6	Longest held occupation (n (%))			
6.1	Manual	14 (34)	16 (41)	
6.2	Non manual	13 (32)	9 (23)	
6.3	Unemployed (able to work)	0 (0)	0 (0)	

Table 19: Valencia: Table of baseline characteristics - long term pathway



Variable	Measurement	Intervention	Control	Difference (p)
6.4	Unemployed (unable to work)	1 (2)	0(0)	
6.5	Homemaker	6 (15)	11 (28)	
6.6	Missing answer	7 (17)	3 (8)	
7	Housing tenure (n (%))			
7.1	Owners	39 (95)	37 (95)	
7.2	Renters	1 (2)	1 (3)	
7.3	Missing answer	1(2)	1 (3)	
8	People older than 18 living in household in addition to the patient <i>(mean (SD))</i>	1,10 (0,5)	1,26 (0,8)	
9	Smoking status (n (%))			
9.1	Never	24 (59)	25 (64)	
9.2	former	16 (39)	10 (26)	
9.3	current smoker	1 (2)	4 (10)	
9.4	e-cigarette	0 (0)	0 (0)	
9.5	Other	0 (0)	0 (0)	
9.6	Missing answer	0 (0)	0 (0)	
10	Alcohol <i>(n (%))</i>			
10.1	None	33 (81)	33 (85)	
10.2	Less than 1/week	7 (17)	1 (3)	
10.3	1-7/week	1 (2)	5 (12)	
10.4	8-14/week	0 (0)	0 (0)	
10.5	15-21/week	0 (0)	0 (0)	
10.6	More than 21/week	0 (0)	0 (0)	
10.7	Missing answer	0 (0)	0 (0)	
11	PC use <i>(n (%))</i>	9 (22)	2 (5)	
12	Mobile phone use (n (%))	24 (59)	20 (51)	
13	Height in cm (mean (SD))	160,5 (8,8)	158,4 (10,9)	
14	Weight in kg (mean (SD))	78,3 (13,2)	74,2 (14,0)	
	Co-morbidity			
15	Primary disease (n (%))			
15.1	Primary disease CHF	20 (49)	20 (51)	
15.2	Primary disease COPD	13 (32)	7 (18)	
15.3	Primary disease DIABETES	9 (22)	8 (21)	
16	Secondary disease (n (%))			
16.1	Secondary disease CHF	4 (10)	3 (8)	
16.2	Secondary disease COPD	5 (12)	8 (21)	
16.3	Secondary disease DIABETES	17 (42)	15 (39)	
17	Social support (n (%))			
17.1	Technical support	7 (17)	2 (5)	
17.2	Logistic support	0 (0)	1 (3)	
17.3	Personal support	2 (5)	2 (5)	
17.4	Loan services support	5 (12)	2 (5)	



Tests	Measurement	Intervention Baseline	Control Baseline	Difference (p)
Barthel index (mean (SD))	Score	76,2 (SD 31,4)	85,4 (SD 21,7)	
Instrumental activity of daily living (IADL) (mean (SD))	Score	3,2 (SD 2,4)	3,8 (SD 2,3)	
Geriatric Depression Scale (GDS) (mean (SD))	Score	3,0 (SD 2,5)	3,2 (SD 2,2)	

Among the 80 care recipients analysed in Valencia Pilot Site, 41 (51%) were in the intervention group and 39 (49%) were in the control group. The distribution of baseline characteristics seems adequately balanced between the intervention and control group.

For demographic characteristics we found that CRs in the intervention and control groups have similar ages, 80 years and 79 years respectively. The intervention group included 61% males, the control group 51% males. Most CRs were either married (66% for intervention group and 65% for control group) or widowed (27% for intervention group and 31% for control group).

The main primary disease for both intervention and control groups was CHF (49% and 51% respectively); the main secondary disease was diabetes for both groups (42% for intervention group and 39% for control group).

In general, is seems as if the intervention group receive more social support than the control group, in particular technical support and loan service support. The difference in social needs between the groups is also supported by the lower Barthel index scoring in the intervention group compared to the control group (lower scores indicating increased disability).

## 4.5 Domain 2&3: Campania

## 4.5.1 Care recipients

Patient care recipients are identified among those that have access to the Assistenza Domiciliare Integrata (Integrated Home Care, ADI) in the Salerno Area. Originally it was planned that the CRs would be recruited also in the Napoli area, but, given local political and organisational constrains, the recruitment has been limited to the Napoli area only. The criteria for the inclusion of the patients are as follows:

- Age ≥65 years.
- Presence of heart failure, stroke, COPD or diabetes (diagnosed in a hospital or specialist) in addition to at least one other disease / chronic condition included in the Charlson Comorbidity Index (CCI).
- The subject would require a level of assistance (LEA) equivalent to Class 1 (low to high) home care, according to the Campania Region-Ministry of Health, Decree.
- Presence of social needs based on Instrumental Activities of Daily Living (IADL) and the appropriate elements of the Barthel scale.
- A reasonable expectation of permanence in BeyondSilos for the entire project.
- Informed consent, signed as decided at the local level, by the person or his/her delegate.
- Ability to manage equipment / ICT devices alone, or with the help of a delegate.
- Presence of a reliable access to the internet, phone or anything else needed to connect ICT.



## 4.5.2 Aims and objectives

#### Aims:

The aim of the Campania pilot site is to exploit the existing solutions of integrated care pathways to respond to complex needs of welfare recipients, as well as the needs of caregivers and institutions, formal or informal, through the support of ICT.

#### **Objectives:**

To analyse the impact on care recipients and professionals resulting from the implementation of integrated actions of health and social care based on ICT, in accordance with the MAST model.

This will be done by examining:

- Difference in the number of hospitalisations during the study, and in the length of hospitalisation; difference in the number of contacts planned / unplanned with health and social care professionals, as well as other informal caregivers (family, third sector, etc.).
- Difference in the empowerment of care recipients.
- Difference in cost, according to a methodology shared with the Council of the project, still being finalised; difference in organisational aspects, as a result of integrated based on ICT.

## 4.5.3 End-user flow and recruitment

The chart describes the process of enrolment patients in the Campania Pilot Site. All procedures were performed in agreement with the personnel of the Local Health Authority of Salerno (ASL Salerno), Department of Home Care. Given the unpredicted unavailability of the ASL Napoli 1, we focused on the recruitment within the Salerno area of all 50 patients receiving home monitoring, as the infrastructural needs for these patients were more demanding. We are now recruiting the "control patient" group, that will be chosen among those that are already enrolled in the ADI program, and will be assessed for the basal intermediate and final assessment as requested by the program. All enrolment will be finished by the end of January 2016.





Figure 10: Campania: Flowchart of participants' paths

## 4.5.4 Baseline characteristics

At the moment (18<sup>th</sup> January 2016), it is not possible to produce a statistical analysis of the two groups since enrolment in the control group has been delayed. The baseline table therefore only includes the available numbers and prevalence for the enrolled care recipients in the intervention group. We expect to be able to update the baseline table with the information from the control group by mid-February 2016.

Table 20: Valencia: Table of baseline	characteristics - long term pathway
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Variable	Measurement	Intervention	Control	Difference (p)
1	Sample size (n (%))	(100)		
2	Age (mean (SD))	80 ()		



Variable	Measurement	Intervention	Control	Difference (p)
3	Gender, male (n (%))	(46)		
4	Marital status (n (%))			
4.1	Never married	(8)		
4.2	Currently married	(52)		
4.3	Separated	(0)		
4.4	Divorced	(0)		
4.5	Widowed	(38)		
4.6	Cohabitating	(0)		
4.7	Missing answer	(2)		
5	Education (n (%))			
5.1	Less than primary school	(0)		
5.2	Primary school	(0)		
5.3	Secondary school	(0)		
5.4	High school	(0)		
5.5	College/University	(0)		
5.6	Post graduate degree	(0)		
5.7	Missing answer	(100)		
6	Longest held occupation (n (%))			
6.1	Manual	(0)		
6.2	Non manual	(0)		
6.3	Unemployed (able to work)	(0)		
6.4	Unemployed (unable to work)	(0)		
6.5	Homemaker	(0)		
6.6	Missing answer	(100)		
7	Housing tenure (n (%))			
7.1	Owners	(54)		
7.2	Renters	(7)		
7.3	Missing answer	(39)		
8	People older than 18 living in household in addition to the care recipient (mean (SD))	3 ()		
9	Smoking status (n (%))			
9.1	Never	(52)		
9.2	former	(38)		
9.3	current smoker	(0)		
9.4	e-cigarette	(0)		
9.5	Other	(0)		
9.6	Missing answer	(10)		
10	Alcohol <i>(n (%))</i>			
10.1	None	(76)		
10.2	Less than 1/week	(0)		
10.3	1-7/week	(0)		
10.4	8-14/week	(0)		
10.5	15-21/week	(0)		
10.6	More than 21/week	(0)		



Variable	Measurement	Intervention	Control	Difference (p)
10.7	Missing answer	(24)		
11	PC use (n (%))	(66)		
12	Mobile phone use <i>(n (%))</i>	(86)		
13	Height in cm (mean (SD))	163 ()		
14	Weight in kg <i>(mean (SD))</i>	71 ()		
	Co-morbidity			
15	Primary disease (n (%))			
15.1	Primary disease CHF	(39)		
15.2	Primary disease COPD	(39)		
15.3	Primary disease DIABETES	(68)		
16	Secondary disease (n (%))			
16.1	Secondary disease CHF	(55)		
16.2	Secondary disease COPD	(46)		
16.3	Secondary disease DIABETES	(31)		
17	Social support (n (%))			
17.1	Technical support			
17.2	Logistic support			
17.3	Personal support			
17.4	Loan services support			

## 4.6 Domain 2&3: Kinzigtal

#### 4.6.1 Care recipients

Persons from social care institutions have been selected to be responsible for the evaluation process. They will operate as case managers. The recruitment process is mainly done by the home care unit of the social care provider, because usually these staff have the best relationship with citizens and convince them to participate in BeyondSilos.

100 patients meeting the inclusion criteria were observed for eligibility for the control group by German Red Cross. 53 of them were included for evaluation based on the criteria described. 35 patients were assessed for eligibility for the intervention group by Seniorenzentrum am Schlossberg based on the inclusion criteria. 30 of them were included. Because the home nursing service is rather new to people living in the region, client numbers are still small.

First eligibility criterion is patients who are in consultation of one of the GPs located in the Hausach region and member of Gesundes Kinzigtal network. Second, identification is based on inclusion and exclusion criteria for evaluation framework from social care record of clients and staff's knowledge about potential persons to participate in evaluation. After identification of the potential recruitment group, the special care manager of the social care provider who is responsible for the evaluation process within BeyondSilos introduces BeyondSilos to clients by doing a home visit. If the client gives permission to join BeyondSilos and has given written consent, the necessary data will be documented using questionnaires or structured interviews. Patients belonging to the control group will get usual treatment from GPs and social care providers. Based on individual needs, the patient receives services such as medication, checking vital parameters, bathing, meals on wheels, accompaniment for administrative purposes, accompaniment to / from hospital, support in household activities, orthopaedic support management, wound management, from once a month to once a day. Patients in the intervention group receive the same care treatment,



but with the support of ICT used by GPs and social care professionals. At the moment, three GP practices are involved working with the new service. Again based on individual needs, health and social care is provided at different frequencies for the patient.

In general, eligibility criteria for end users are:

- A person with both health and social needs who will be provided with both health and social care by local GPs around Hausach.
- Enrolled in network of Gesundes Kinzigtal.
- A person who has signed informed consent.

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

- Age ≥65 years.
- Presence of health needs, specified as:
  - Presence of heart failure, stroke, COPD or diabetes (diagnosed at hospital or at specialist visit) plus at least one additional chronic disease / condition included in the Charlson Comorbidity Index (CCI).
  - Presence of social needs based on Instrumental Activities of Daily Living (IADL) and appropriate items of Barthel scale.
- Reasonable expectation of permanence in the BeyondSilos project for the whole period.
- Presence of good / reliable communication connection at home: internet, telephone or whatever is needed for the ICT connection.

#### 4.6.2 Aims and objectives

#### The aims are:

- To optimise the care continuum for elderly care recipients with multiple co-morbidities and social needs by providing an electronic shared care platform for professionals working in the healthcare and social sectors in order to improve the information flow between the two sectors.
- To give CRs a higher feeling of safety in their care and a higher quality of information between caregivers.
- To provide a common framework that allows the coordination of care records between health and social care professionals, along with a common patient data set for patients long term at home.

**The objective** of the BeyondSilos intervention in Kinzigtal is to evaluate the effect of introducing a shared electronic patient record for health and social care professionals caring for CRs receiving health and social care. This will be done by examining the economic and organisational impact of the new integrated service and its acceptability by care recipients and professionals.

- For the effect on organisational structure, workflows and satisfaction of professionals, it is planned to measure the number of contacts between health and social care givers and CRs. Semi structured interviews will give a deeper view on satisfaction and acceptability.
- To evaluate the economic impact on health care costs, it is necessary to compare the number and type of hospital admissions and home visits of healthcare professionals.
- To analyse the effect on patient safety in their care, activities of daily living will be compared between intervention and control group; semi structured interviews will be held with CRs.



### 4.6.3 End-user flow and recruitment



Figure 11: Kinzigtal: Flowchart of participants' paths

#### Description flow chart Gesundes Kinzigtal:

Intervention group and control group are recruited from two different social care institutions. The control group is selected by Red Cross and the intervention group by Seniorenzentrum am Schlossberg. The eligibility process for the intervention group started in January 2015 with asking potential participants and filling out written consent. Recruitment for the intervention group is still going on. Final numbers are expected to be reached by end of February 2016. The control group eligibility process started August 2015, including receiving written consent and obtaining baseline data. In both groups 135 participants were asked to participate. 47 clients declined to participate. Another five clients were eligible, but their assigned GP did not participate in the BeyondSilos project, so they could not therefore participate. Finally, 30 clients were enrolled into the intervention group and 53 into the control group. Two clients in the



control group were lost to follow-up. One unfortunately died, and the other was admitted to a nursing home and therefore excluded from the BeyondSilos programme. Because the home nursing service of Seniorenzentrum am Schlossberg is rather new to people living in the region, client numbers are still small, and consequently so are recruitment numbers for the intervention group.

### 4.6.4 Baseline characteristics

Table 21: Kinzigtal: Table of baseline cl	haracteristics
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Variable	Measurement	Intervention	Control	Difference (p)
1	Sample size (n (%))	30 ()	53 ()	
2	Age (mean (SD))	85 ()	83 ()	
3	Gender (male) <i>(n (%))</i>	6 (27)	19 (40)	
4	Marital status (n (%))		I	
4.1	Never married	1 (3)	8 (15)	
4.2	Currently married	3 (10)	18 (34)	
4.3	Separated	0 (0)	0 (0)	
4.4	Divorced	0 (0)	1 (2)	
4.5	Widowed	22 (74)	25 (47)	
4.6	Cohabitating	0 (0)	1 (2)	
4.7	Missing answer	4 (13)	0 (0)	
5	Education (n (%))			
5.1	Less than primary school	0 (0)	14 (21)	
5.2	Primary school	0 (0)	35 (70)	
5.3	Secondary school	2 (7)	3 (6)	
5.4	High school	0 (0)	1 (2)	
5.5	College/University	0 (0)	0 (0)	
5.6	Post graduate degree	0 (0)	0 (0)	
5.7	Missing answer	28 (93)	0 (0)	
6	Longest held occupation (n (%))			
6.1	Manual	0 (0)	27 (51)	
6.2	Non manual	3 (10)	9 (17)	
6.3	Unemployed (able to work)	0 (0)	0 (0)	
6.4	Unemployed (unable to work)	0 (0)	1 (2)	
6.5	Homemaker	2 (7)	16 (30)	
6.6	Missing answer	25 (83)	0 (0)	
7	Housing tenure (n (%))			
7.1	Owners	8 (27)	34 (64)	
7.2	Renters	8 (27)	19 (36)	
7.3	Missing answer	14 (46)	0 (0)	
8	People older than 18 living in household in addition to the care recipients (mean (SD))	0 (0)	35 (66)	
9	Smoking status (n (%))			
9.1	Never	13 (43)	37 (70)	
9.2	former	0 (0)	12 (23)	
9.3	current smoker	1 (3)	1 (2)	



Variable	Measurement	Intervention	Control	Difference (p)
9.4	e-cigarette	0 (0)	0 (0)	
9.5	Other	0 (0)	0 (0)	
9.6	Missing answer	16 (54)	3 (5)	
10	Alcohol (n (%))			
10.1	None	12 (40)	23 (43)	
10.2	Less than 1/week	0 (0)	19 (36)	
10.3	1-7/week	1 (3)	8 (15)	
10.4	8-14/week	0 (0)	0 (0)	
10.5	15-21/week	0 (0)	0 (0)	
10.6	More than 21/week	0 (0)	0 (0)	
10.7	Missing answer	17 (57)	3 (6)	
11	PC use (n (%))	2 (7)	6 (11)	
12	Mobile phone use (n (%))	4 (13)	15 (28)	
13	Height in cm (mean (SD))	159 ()	163 ()	
14	Weight in kg <i>(mean (SD))</i>	74 ()	73 ()	
		Co-morbidity		
15	Primary disease (n (%))			
15.1	Primary disease CHF	10 (33)	43 (81)	
15.2	Primary disease COPD	0 (0)	3 (6)	
15.3	Primary disease DIABETES	4 (13)	5 (9)	
16	Secondary disease (n (%))			
16.1	Secondary disease CHF	1 (3)	0 (0)	
16.2	Secondary disease COPD	1 (3)	0 (0)	
16.3	Secondary disease DIABETES	1 (3)	3 (6)	
17	Social support (n (%))			
17.1	Technical support	15 (50)	22 (42)	
17.2	Logistic support	16 (53)	37 (70)	
17.3	Personal support	19 (63)	53 (100)	
17.4	Loan services support	15 (50)	45 (4)	

Tests	Measurement	Intervention Baseline	Control Baseline	Difference (p)
Barthel index	Score	27 (SD)	23 (SD)	
Instrumental activity of daily living (IADL)	Score	23 (SD)	23 (SD)	
Geriatric Depression Scale (GDS)	Score	25 (SD)	24 (SD)	

The baseline table was completed on 10<sup>th</sup> December 2015. Any CRs included or lost to follow-up after this date have not been included in the table above. However, they will be included in the final evaluation of Kinzigtal. Information on statistical differences between the control and intervention groups has not been included in this baseline table since all CRs have not yet been enrolled.

A total of 83 participants are included in the baseline table. 30 participants were assigned to the control group and 53 to the intervention group. The mean age of the intervention and control groups is nearly the same; mean ages are 85 and 83 years respectively. The gender distribution between the two groups



seems to be more different; in the intervention group, only 27% are males, whereas in the comparison group there are currently 40% males. Regarding technical support both groups are similar; approximately half of the care participants are in need of technical services in their home; more precisely, 50% in the intervention group and 42% in the control group. In terms of logistic support, the difference seems larger; a little over half of participants in the intervention group (53%) require logistic support, while 70% are dependent on logistic support in the control group. Personal support is received by everyone in the control group, but only just over half (63%) in intervention group. Regarding loan services, the differences do not seem very large; in the intervention group, exactly 50% of participants are in need of those services, compared with just under half of control group (43%).

Of interest, it seems that CRs in the intervention group who have been enrolled by Seniorenzentrum am Schlossberg are more likely to give missing answers than participants in the control group who have been enrolled by the German Red Cross county chapter Wolfach. Gesundes Kinzigtal has already obtained missing answers from Seniorenzentrum am Schlossberg in December 2015, after the table above was completed.

## 4.7 Domain 2&3: Amadora

## 4.7.1 Care recipients

In Amadora Piot Site, the following criteria for eligibility were defined:

- Social care:
  - Benefiting from Home Care Support of Misericiordia of Amadora.
  - +65 living alone.
  - Living with partner, siblings or older relatives.
  - Living with dependent people at home.
  - With home care needs or at risk of exclusion due to illness or disability of any condition.
  - Elderly people discharged from hospital.
  - Lack of resources at home.
  - Main carer in hospital.
  - Lack of relatives during hospital admission or during the first 2 days.
- Health care:
  - +65.
  - Benefiting from Home Care Support of Misericiordia of Amadora.
  - Patients discharged early from hospital.
  - Mainly suffering from diabetes and stroke.
  - Any other surgery that may demand cars and rehabilitation at home.
  - Terminal neoplastic or neoplastic illness.
  - Dementia and / or psychological handicap.
  - Lack of support at home.
  - With home care needs or at risk of exclusion due to illness or disability of any condition.
  - Autonomous or in a dependency situation.

The target group defined for the Project consists of 150 clients, which means that the Coordination Team should guarantee that at any time of the Project 150 clients are being monitored under ADS services.

All the clients enrolled in the Project must have previously signed an Informed Consent Form.



Main services provided on site will consist on the following:

- Accompaniment for administrative purposes.
- Accompaniment to / in hospital.
- Accompaniment at home.
- Administrative tasks.
- Home care support.
- Tele-assistance (panic button).
- Telemonitoring.
- Meals at home.
- Cleaning.
- Home maintenance and repairs.
- Follow-up agenda.
- Wheel chair / crutch / articulated bed loan.
- Volunteering service: company and ludo pedagogical activities.
- Coordination healthcare centre / hospital.

#### 4.7.2 Aim and Objectives

#### Aims:

- To increase the quality of life of the care recipients, enhancing the possibility to continue living at home.
- To improve the quality of the services provided at home and efficiency, through the introduction of ICT.

#### **Objectives:**

BeyondSilos will play a crucial role in Amadora with regards to the introducing of ICT tools and systems of on-site health and social care to improve the quality of the services provided to elderly people living at home. So far, there is no telemonitoring, and no structured system of care planning. So, the main objectives are the following:

- To enhance the quality and efficiency of the services provided by Misericordia of Amadora in terms of the home care support.
- To reduce the institutionalisation of elderly people given the absence of healthcare at home.
- To involve other key stakeholders in the provision of the social and health care, such as the Amadora Municipality, and ICT providers such as Portugal Telecom.
- To enhance communication between the silos of social and health care.
- To train the formal and informal carers in the heath and social ICT systems and tools.
- To develop a socio-economic impact study in terms of the future sustainability of the model.
- To transfer the model to other organisations and territories.



### 4.7.3 Care-recipient flow and recruitment



Figure 12: Amadora: Flowchart of participants' paths

In Amadora, both control and intervention group are the same. The main reason for this is that Misericordia of Amadora wanted to involve 100% of the Home Care Support clients in the project, in order to enhance their quality of life. According to this, the intervention period started 8 months before the intervention phase (November 2015). This delay was related to the administrative and bureaucratic process of the acquisition of Portugal Telecom, which delayed all the process of developing and delivering the solutions. This means that the piloting phase started in November but only entered in force in December, which means that it is now in an early phase, so the results so far are not yet too robust.

During the transition from control to intervention phase, 11 clients dropped out, for the following reasons: four have died; six have moved to other regions; and one wanted to give up the service. As a result of this, the Coordination Team has started recruiting new clients, and is planning to have the 150 end users by early February 2016.



#### 4.7.4 Baseline characteristics

At the moment, (20<sup>th</sup> January 2016), it is not possible to produce a statistical analysis for the two groups due to the delay in starting the pilot, related to the administrative and bureaucratic acquisition of Portugal Telecom and the consequent delay in delivering the online platform and telemonitoring systems and devices. The baseline table will be prepared by the second week of February 2016.

## 4.8 Domain 2&3: Sofia

#### 4.8.1 Care recipients

Care recipients were selected for the pilot via two admission entry points: Social referral, from state social service record in Triadica Municipality, and health referral from the GP or from Divaro medical centre.

People selected were aged 65 +, lacking support at home (people living alone) with need of home care and assistance, or being in risk of exclusion due to illness or disability, autonomous in self services, have at least one chronic heart disease, and be a resident of Triadica Municipality.

After assessment of eligibility and recruitment, but before the BeyondSilos intervention begins, the subjects were randomly allocated into two groups - intervention and controls. The selected patients were referred to the CPRH Evaluation Commission to evaluate their status and needs of each individual, and to enable the required services.

#### 4.8.2 Aim and objectives

#### Aim:

To improve care for the elderly with multiple co-morbidities and social needs by providing combined continuous health and social care using new ICT for constant follow up of health and social indicators and needs. To compare the effectiveness of the new services in improving specific outcomes (patient satisfaction, morbidity, acute events, mortality) compared to those that have not received the BeyondSilos intervention, but only usual care from Bulgarian health and social services.

#### **Objectives:**

To apply and assess the effect of introducing combined health and social care, using new ICT, by:

- Comparing differences in morbidity events between care recipients receiving the new BeyondSilos intervention and participants receiving the usual care.
- Comparing differences in mortality rates between care recipients receiving the new BeyondSilos intervention and participants receiving the usual care.
- Comparing changes in activities of daily living between care recipients receiving the new BeyondSilos intervention and participants receiving the usual care.
- Examine the economic and organisational impact of the new integrated service.
- Assess the acceptability by care recipients and professionals.
- Assess the satisfaction of care recipients, relatives and professionals.



### 4.8.3 End-user flow and recruitment



Figure 13: Sofia: Flowchart of participants' paths

The enrolment process at Sofia pilot site started in November 2014. Actual enrolments started in February 2015. The process has been co-ordinated by CPRH, but the field work was performed by our subcontractor, the Family Policy Institute.

The first phase included selection of 200 prospective participants in BeyondSilos and obtaining data for them. The data was provided by three municipal social services, two GP practices, and one hospital.

The subsequent review of the documentation excluded 63 persons as not meeting the inclusion criteria. Another 30 persons were approached but refused to participate, most of them stating that they would not be able to operate new ICT. Another seven persons could not be found to be interviewed at the address provided.

The final figure of 100 participants was reached in October 2015.



## 4.8.4 Baseline characteristics

Variable	Measurement	Intervention	Control	Difference (p)
1	Sample size (n)	50	50	
2	Age Mean (mean (SD))	75 (6.6)	77 (6.1)	
3	Gender, male (n (%))	8 (16)	10 (20)	
4	Marital status (n (%))			
4.1	Never married	0 (0)	0 (0)	
4.2	Currently married	0 (0)	0 (0)	
4.3	Separated	0 (0)	0 (0)	
4.4	Divorced	16 (32)	10 (20)	
4.5	Widowed	32 (64)	39 (78)	
4.6	Cohabitating	2 (4)	1 (2)	
4.7	Missing answer	0 (0)	0 (0)	
5	Education (n (%))			
5.1	Less than primary school	0 (0)	0 (0)	
5.2	Primary school	0 (0)	0 (0)	
5.3	Secondary school	0 (0)	0 (0)	
5.4	High school	6 (12)	11 (22)	
5.5	College/University	16 (32)	18 (36)	
5.6	Post graduate degree	28 (56)	21 (44)	
5.7	Missing answer	(0)	(0)	
6	Longest held occupation (n (%))			
6.1	Manual	8 (16)	10 (20)	
6.2	Non manual	42 (84)	40 (80)	
6.3	Unemployed (able to work)	0 (0)	0 (0)	
6.4	Unemployed (unable to work)	0 (0)	0 (0)	
6.5	Homemaker	0 (0)	0 (0)	
6.6	Missing answer	0 (0)	0 (0)	
7	Housing tenure (n (%))			
7.1	Owners	39 (78)	41 (82)	
7.2	Renters	11 (22)	9 (18)	
7.3	Missing answer	0 (0)	0 (0)	
8	People older than 18 living in household in addition to the patient <i>(m</i> ean (SD))	0 (0.2)	0 (0.35)	
9	Smoking status (n (%))			
9.1	Never	29 (58)	28 (56)	
9.2	former	17 (34)	16 (32)	
9.3	current smoker	4 (8)	6 (12)	
9.4	e-cigarette	0 (0)	0 (0)	
9.5	Other	0 (0)	0 (0)	
9.6	Missing answer	0 (0)	0 (0)	

Table 22: Sofia: Table of baseline characteristics - long-term pathway



Variable	Measurement	Intervention	Control	Difference (p)
10	Alcohol (n (%))			
10.1	None	41 (82)	39 (78)	
10.2	Less than 1/week	6 (12)	7 (14)	
10.3	1-7/week	3 (6)	4 (8)	
10.4	8-14/week	0 (0)	0 (0)	
10.5	15-21/week	0 (0)	0 (0)	
10.6	More than 21/week	0 (0)	0 (0)	
10.7	Missing answer	0 (0)	0 (0)	
11	PC use (n (%))	17 (34)	13 (26)	
12	Mobile phone use (n (%))	48 (96)	42 (84)	
13	Height in cm <i>(m</i> ean (SD))	167 (7.9)	169 (8.3)	
14	Weight in kg <i>(m</i> ean (SD))	71 (14.5)	72 (14.8)	
	Co-morbidity			
15	Primary disease (n (%))			
15.1	Primary disease CHF	36 (72)	33 (66)	
15.2	Primary disease COPD	2 (4)	4 (8)	
15.3	Primary disease DIABETES	12 (24)	13 (26)	
16	Secondary disease (n (%))			
16.1	Secondary disease CHF	27 (54)	32 (62)	
16.2	Secondary disease COPD	15 (30)	6 (12)	
16.3	Secondary disease DIABETES	8 (16)	13 (26)	
17	Social support (n (%))			
17.1	Technical support	0 (0)	0 (0)	
17.2	Logistic support	43 (86)	40 (80)	
17.3	Personal support	12 (24)	13 (26)	
17.4	Loan services support	6 (12)	5 (10)	

The baseline table above has been compiled with data available up until 8<sup>th</sup> January 2016. Any participants included after this date have not been included in this version of the baseline table.

The data in the table reflects the baseline characteristics of 100 care recipients -50 in the intervention group and 50 in the control group.

The majority of participants are women, because of the longer life expectancy of women and the general receptiveness of women to new social services.

## 4.9 Domain 2&3: Northern Ireland

The evaluation of the BeyondSilos pilot in Northern Ireland will focus on the impact of the Shared Care Summary (SCS) in the Northern Ireland Electronic Care Record (NIECR). Because the pilot involves building the SCS into the actual, live NIECR, all integration work is dependent on the timescales and work ongoing in the live system.

Implementation of the SCS has been significantly delayed due to an upgrade of the NIECR system which was fully implemented on 16<sup>th</sup> December 2015. Following this upgrade, the SCS is on the workplan roadmap for Orion (ECR contractor), and it is now likely to happen at the end of February 2016 (information available as at 13<sup>th</sup> January 2016). As a result of this unavoidable delay, it has not been



possible to start collecting baseline information yet; it is hoped to start this data collection at the start of March 2016.

#### 4.9.1 Care recipients

Patients selected for the SCS pilot will be identified by participating GP practices. They will be aged over 65 years and will have at least one long-term condition, at least one co-morbidity, and also a social care need. Dr Brendan O'Brien, HSCB, has carried out a risk stratification analysis on GP patient lists, and has provided practices with their individual risk stratified lists in December 2015; participating practices will select 14 patients from this list for SCS intervention and 14 similar patients for control. Individual practices will be free to choose patients for each cohort provided they meet the criteria listed above.

## 4.9.2 Aims and objectives

#### Aim:

To optimise the care continuum for elderly care recipients with multiple co-morbidities and social needs by providing a Shared Care Summary within the NIECR for professionals working in health and social care in order to improve the information flow between care professionals working across different sectors.

#### **Objectives:**

To examine the effect of introducing a Shared Care Summary for health and social care professionals caring for people with complex health and social care needs assessed as being at high risk of admission and readmission to secondary care.

This will be done by:

- Comparing differences in numbers and types of contacts with the healthcare and social care system between CRs receiving the new BeyondSilos service and participants receiving the usual care.
- Comparing differences in mortality rates between CRs receiving the new BeyondSilos service and participants receiving the usual care.
- Comparing changes in activities of daily living between CRs receiving the new BeyondSilos service and participants receiving the usual care.
- Examine the economic and organisational impact of the new integrated service and the acceptability by CRs and professionals.

#### 4.9.3 End-user flow and recruitment

Because of the unavoidable delay in building the Shared Care Summary into the NIECR, no patients have yet been recruited into the pilot; this section will be completed in March 2016.

#### 4.9.4 Baseline characteristics

Because of the unavoidable delay in building the Shared Care Summary into the NIECR, no patients have yet been recruited into the pilot; this section will be completed in March 2016.



## 5 Conclusion on status and input

All sites have successfully described Domain 1 in the MAST model "Health and social situation of the care recipients and characteristics of the service" (modified version for integrated care). The description of Domain 1 includes information from all pilot sites on: The health and social situation of the care recipient, quantification of the health and social situation of the care recipient, the management of the health and social situation, the ICT solution supporting integrated care, the technical characteristics of the service, and the requirements for use of the ICT solution.

The description of domains 2 & 3 includes information on participant flow and enrolment, aims and objectives and baseline characteristics for the first participants enrolled. The description includes information both at an individual site level but also an overall view with some preliminary comparisons of the distributions of selected baseline variables. With the exception of Northern Ireland and Amadora, all pilot sites have started uploading data to the central database, and have begun the preliminary data analyses of the baseline data. Both Northern Ireland and Amadora are expecting to start data upload by the end of February 2016.

Most pilot sites have had minor delays in the enrolment of participants and data upload to the central database. Therefore, the report only includes the enrolled participants as of mid-January 2016.



# Appendix A: Measures of actual social care provided

Functional disabilities generate a series of social care interventions for people requiring this type of support. The most common services provided include:

- Tele-assistance (panic button).
- Personal tracking (by GPS when going outdoors).
- Meals at home.
- Cleaning at home.
- Laundry service.
- Home care support (delivered by family workers).
- Accompaniment to meetings (either for medical reasons or administrative matters).
- Risk exclusion avoidance (by programming activities in the diary).
- Home fixings and repairs (free or with a co-payment).
- Access to loan services (wheel chairs, adapted beds, etc...).

Within this framework, in addition to the IADL scale, in BeyondSilos these types of services are included in the codebook (variables to be measured during the follow up), grouped into four categories, which describe social demand and offer, as evaluated at start and end of the observation period. These are identified by Y/N to four questions:

- Does the participant have technical support such as panic button, GPS tracking?
- Does the participant have logistic support such as meals, cleaning, and laundry, home repairs?
- Does the participant have personal support such as family workers, day care centres, punctual accompaniment (to medical visits), company for risk exclusion avoidance?
- Does the participant have loan services support such as wheel chairs, crutches, adapted bed?

The first question investigates the possible presence of technical support. In recent years it has become a common practice to organise telecare, supported by basic technologies that enable the person to promptly activate an aid in case of emergency (typically, falls) or to be traced when outdoors.

The second deals with the most frequent social support services provided to the users, who have difficulties in these basic daily activities and thus need help and support.

The third relates to other possible facilities that are required / offered to protect the person.

The fourth collects information on the tools that can support a disability and give the opportunity to (at least partially) live in a more independent way, despite functional limitations.

Using these four domains considered at start and end of the pathway, it is possible to recognise how the "functioning" of the assisted person is changing through the follow up, taken together with the global effects of the diseases and the social impairments.



## Appendix B: Badalona: Background information

To better understand the descriptions provided in the context of the evaluation framework, a brief introduction to the organisation may be needed.

Badalona Serveis Assistencials (BSA) is an integrated private health and social care organisation with entirely public capital that manages the Hospital Municipal de Badalona, the Homecare Integrated service, the socio health centre El Carme, seven primary care centres and the Centre for Sexual and Reproductive Health. It provides care to a total population of 419,797 inhabitants in a very populated suburban area of Barcelona.



Figure 14: Distribution of BSA's centres among the cities of Badalona, Montgat and Tiana

BSA has a special characteristic that distinguishes it from all the other healthcare providers in Catalonia: it also provides the social care services for the region of Badalona and three other towns surrounding it. Originally in our country, a separation between the Department of Social Welfare and Family and the Department of Healthcare has existed. In terms of welfare, this separation has not proven to be the most suitable to provide effective and quality care to the patient who receives both types of care simultaneously. Because of that, in year 2000, it was decided between BSA and the city Council of Badalona to change the conceptual model, centring it on the patient. This model was carried out at the operating level by transferring social services to BSA, a company originally dedicated to the provision of health services, thus obtained the perfect fusion between the conceptual and operational level.

The union of the older healthcare-oriented infrastructure (the Geriatric Department) dealing with all kinds of elderly typologies ranging from the healthy, the frail, ill, dependent or those in a late stage of life, along with a public Social Service department, renders BSA able to complement health-related interventions with social assistance on a level of almost unprecedented process consolidation. This situation, as a whole, effectively makes BSA work as an integrated care organisation, not only taking into account the vertical integration among the three classic healthcare levels, but also integrating horizontally with the social services which makes the organisation being able to deal with and manage the complete social welfare situation among the whole reference population. The structure of the organisation unit, located at the Hospital Municipal de Badalona; the Socio-Health Care unit and a Home Care Service; and all supported by state-of-the-art technology.

The provision of care in BSA has changed within the years following the natural evolution of every healthcare organisation and the needs & demands from the community / population: moving towards



implementing best practices with the main aim to improve the quality of the services provided to its target population while ensuring the sustainability of the system. But, further to that natural evolution, BSA experienced a situation that changed its essence, transforming it from a comprehensive healthcare organisation (which vertically integrated the three classic levels of healthcare) to an integral care organisation (which also included the provision of the social services) and effectively closed the care provision loop around the patient.

To understand that big change in the conceptualisation of the provision of care at BSA, two key moments should be highlighted:

- Year 2000: The social services were entrusted to BSA.
- Year 2003: The Homecare Service was created in order to provide and coordinate the provision of care, as requested by the population.

At year 2000, there was very few knowledge on how to implement a comprehensive provision of care. The scientific literature was poor or non-existing and previous experiences at such a big scale as the one meant to be provided by BSA totally unknown. Further to that, the digitalisation of the social services was totally inexistent compared to the healthcare infrastructure, which was already totally digitalised and integrated since year 1995.

Up to that point BSA followed a double strategy: one the one side designing the new service provision and on the other side to provide from the necessary ICT to support it. The representation of the first one was through a new strategic plan, which included a clear definition of the aims of the organisation, thus the will to continuously monitor and improve the service provided and the creation of the Homecare Department. The second one was represented by the creation of the Social Care Record (SCR) and the Homecare Department management software, which sits in the middle of the Electronic Health Record (EHR) and the SCR. Further explanation about the ICT solution already in place can be found in the section "Description of the ICT solution (technology)".

After that big essential change in the nature of the organisation, and the start of the full implementation of the new model in year 2003, one may say that the main characteristic of the provision of care in BSA is that it is organised through a patient centred model, which effectively means that the services are tailored according to the patient's specific needs. Even so, there are some generic services that have been evolving within the years since the Homecare Service was born, which can be seen in Figure 15.



Figure 15: Evolution of the different services provided by the Homecare service and the different strategic plans supporting it

BeyondSilos



# Appendix C: Tables of integration level

This appendix presents the detailed results of the self-assessment process carried out by each site, as described in section 3.5 (page 22).

In the left panel of the table cells quote the scores of the degree of interactions and integrations within and between actors. The scoring system aims to reduce inter- and intra-variabilities of local self-estimates of the team. Items are as follows (abbreviation used in brackets):

- None (No): No interaction between sectors/actors (including spontaneously or informally interaction).
- Low (L): Only spontaneous or informal integrated practices. No formal agreements in place.
- **Medium (M)**: Some formal agreements/rules are in place. However, interactions between sectors/actors occur in routine practice more spontaneously and informally (more than for low interaction) rather than planned.
- **High (H)**: Formal agreement in place. Clear workflow between actors defined; ICT solutions are positively integrated and are part of the work routine.
- Added value (a): This only applies when an improvement is estimated but not up to a "higher level" (e.g. not reached all requirements of the above item). A short description can be used.
- Unchanged (u): This only applies when the level of integration remained unchanged, irrespective from the starting point (has remained unchanged because of, for example, lack of time, no strategy-commitment ad hoc, good starting value, etc.).
- NA: not applicable.

On the whole, the table indicates in a pragmatic-visual way how the application of BeyondSilos care pathways might reciprocally influence integration/interactions between various stakeholders, namely: health services, social services, services delivered by third sectors and non-institutional providers (named as "others") and, obviously, the person/care recipient and her/his family (intended as on the whole the family entourage). In the matrix scores reflect bilateral point of view (i.e. "A" versus "B", and vice versa, since the two points of view could be not coincident), indicating both different perception of relationships.

Sites were asked to perform the assessments with the same evaluator (generally the local coordinator) at the two steps, in agreement with the local integrated care team, so to obtain shared opinions and reduce personal-isolated view.

Since this is a qualitative approach, <u>no comparisons between sites are appropriate</u>. This multi-point selfevaluation method has value only by considering the temporal trends in the individual site, thus with an intra- rather than an inter-sites confrontation. These tables aim to highlight changes (improvements in red) occurred. Scoring values at mid-term represent "facts" (new status reached; no expectations at start).

The changes reported occurred from the start (first column) of the BeyondSilos project until 15th of February (second column). A third step will be repeated at the end of the project period (third column, final).

The right panel of the table provides a more detailed quantitative summary of the changes in different starting levels of scores, in order to offer a clear comprehensive view of the trends. The graph shows the variations of percentage changes at each level of scores. Both can clarify the general assumption that, with rare exceptions, the higher the starting level the lesser the probability/possibility to further improve it.

Finally, the total number of scores improved vs baseline is also provided.

## C.1 Badalona

	Не	alth	S.	Sc	ocial	S.	Т	hird	S.	Ot	her	pr.	PE		<b>N</b>	F	AMI	LY		si	art	n	nid		fin	al
BADA	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final		n	%	n		%	n	%
HIth S	Н	а		Н	а		L	Н		Н	а		Н	u		Н	u		none	8	25	7		22		
Soc S	Н	а		Н	а		L	Н		L	u		Н	u		Н	u		low	6	19	3		9		
Third	L	н		L	н		No	L		No	u		Н	u		Н	u		medium	0	0	0		0		
Other	Н	а		L	u		No	u		No	u		No	u		No	u		high	18	56	22		69		
Pers	Н	u		Н	u		Н	u		No	u								added*			6		19		
Fam	Н	u		Н	u		Н	u		No	u								*added	alue to 6 st	arting high	level				
																			n. tot. sc	ores impro	ved=11/32 (	34%)				

The point of departure for the integration levels for BSA was already pretty high, which has made the room for improvement more difficult. Even so, there is an improvement of integration in 34% of the total possibilities. As shown in the table and graph, "low level" decreased from 19% to 9%, whereas "high level" increased from 56% to 69%. This happened specifically because of the integration of the third sector care providers into the provision of care, moving the parameters of this stakeholder from a low level of integration to high. At the same line, relationships between some of the third sector care providers operating in the Community have started thanks to the BeyondSilos provision of care where nothing was happening before. Secondly, the introduction of the telemonitoring solution into routine care has also added value to the integration between third party providers and the third sector.





## C.2 Valencia

	He	alth	S.	Sc	ocial	S.	Т	hird	S.	Ot	her	pr.	PE	RSC	<b>N</b>	F.	AMI	LY		st	art	m	id		fin	al
VAL	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final		n	%	n	9	6	n	%
HIth S	Н	а		no	Н		no	u		L	u		Н	а		М	Н		none	4	13	2	ť	5		
Soc S	no	H		Н	а		L	u		L	u		м <b>Н</b> м				Н		low	18	56	18	5	6		
Third	no	u		L	u		L	u		L	u		L	u		L	u		medium	6	19	0	(	)		
Other	L	u		L	u		L	u		L	u		L	u		L	u		high	4	13	12	3	8		
Pers	Н	а		М	н		L	u		L	u								added*			4	1	3		
Fam	М	н		М	н		L	u		L	u								*added va	lue to 4 sta	rting high le	evel				
																			n. tot. scor	es improve	d=10/32 (3	1%)				

In the Valencia site, we observe an improvement of 31% in integration. Note that "low" level remain unchanged, whereas "high" level increased (up to 38%), with a positive trend even when the starting level was high, as demonstrated by four "added value" in the baseline category "high". There was a decrease in "none" interaction from 13% to 6% and with six shifted from "medium" level to "high" level.

The most important improvement is that end users of BeyondSilos service have covered the social perspective whereas previously they did not have this service. All fields regarding to social care has grown where they were put in place. Also, the introduction of ICT has improved the interactions between patient and healthcare, and between caregiver/family and healthcare- they feel better connected with their healthcare services. Integration between social and healthcare providers enriches the patient's information in both ways.





%

13

50

13

19

6

final

n

%

mid

n

4

16

4

2

#### **C.3** Campania

	He	alth	<mark>s.</mark>	So	ocial	S.	Т	hird	S.	Ot	her	pr.	PI	ERSC	<b>N</b>	F/		LY		sta	art	
CAMP	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final		n	%	
HIth S	М	Н		L	а		no	u		no	u		М	н		М	н		none	4	13	
Soc S	L	а		М	Н		L	u		no	u		L	Μ		L	Μ		low	22	69	
Third	no	u		L	u		L	u		L	u		L	u		L	u		medium	6	19	
Other	L	u		L	u		L	u		L	u		L	u		L	u		high	0	0	
Pers	М	Н		L	Μ		L	u		L	u								added			
Fam	М	Н		L	Μ		L	u		L	u											
																			n. tot. sco	res improv	ed=12/32	(38%)

There is an increase in the level of interaction between all the actors with the health system, with particular regard to "high" level (six cases at mid -term in vs none at the start). We estimated an increase in "high" level quality of integration from 0% to 19% of possibilities. This is based on the fact that the health sector is the one where the most of the investment is done at the moment. Indeed, municipalities, responsible for social care, have made the least investment, and there is still a need for more social workers. The Third sector is under-represented in this site, where family and relatives are most in charge of the informal patient care. For these actors, we have observed an increase in the interaction due to the empowerment of informal carers and patients toward the case itself.





## C.4 Kinzigtal

	Health S.			So	ocial	S.	T	hird	S.	Ot	her	pr.	PI	RSC	<b>N</b>	F/	AMI	LY			sta	art	mid		fir	nal
KINZ	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final			n	%	n	%	n	%
HIth S	Н	Η		М	Н		L	u		L	u		М	Н		L	Μ		no	one	0	0	0	0		
Soc S	L	Μ		М	н		М	u		L	u		М	u		М	u		lov	w	20	63	14	44		
Third	L	u		М	u		М	u		L	u		М	u		L	u		me	edium	11	34	14	44		
Other	L	u		L	u		L	u		L	u		М	u		М	u		hig	gh	1	3	4	13		
Pers	L	Μ		L	Μ		L	u		L	u								ad	ded						
Fam	L	Μ		L	Μ		L	u		L	u															
																			n. 1	tot. score	es improve	d=9/32 (28	8%)			

On the whole, there is an improvement of interaction in 9 (28%) of the total possibilities. The "low" level decreased from 63% to 44%, whereas "high" level increased from 3% to 13%. Interactions were increased in terms of relations between social sector and health care sector thanks to the new services of both sectors. "High" level increased in limited cases because there was already a good starting point between healthcare professionals, already using a well-established shared electronic patient record. On "medium" level, there is an increase from 34% to 44%. At the final end-point, we are expecting to achieve a higher increase of "high" level. Because of lack of routine using the new service, in this phase of the project we observe only a change from "low" to "medium" level. Unchanged situations relate to the majority of stakeholders' relations, since BeyondSilos interventions cannot affect them.





## C.5 Amadora

	Health S.			So	ocial	S.	Т	hird	S.	Ot	her	pr.	PI	ERSC	<b>DN</b>	F	AMI	LY			st	art	mid		fir	nal
AMAD	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final			n	%	n	%	n	%
HIth S	М	н		L	Н		М	Н		М	н		L	н		L	н		no	one	0	0	0	0		
Soc S	L	н		М	Н		М	Н		М	н		М	н		М	Н		lov	w	9	28	2	6		
Third	М	н		М	Н		М	Н		L	н		М	н		М	н		me	edium	23	72	3	9		
Other	М	н		М	Н		М	Н		М	u		М	u		М	u		hi	igh	0	0	27	84		
Pers	L	Н		М	Н		М	Н		L	u								ad	dded						
Fam	L	н		М	Н		М	Н		L	u															
													-						n.	tot. sco	res improv	/ed=27/32	(84%)			

There is an improvement of interaction in 27 (84%) of the total possibilities. "Low" level decreased from 28% to 6%, whereas "high" level increased from 0% to 84%, thanks also to a shift from "medium" to "high" level. These significant and relevant results are explained by the total new service process model introduced by Beyond Silos in Amadora, described below.

In Amadora, and regarding the services provided by the Home Care Support Services, there was no previous integration between social and health services. Before BeyondSilos, the organisations have been "just" providing social services, namely hygiene, food and medication. Accordly, BeyondSilos has been playing a very important role not only for Misericordia of Amadora as services provider, but also for the other services providers that could benefit, in the future, from the testing and boosting of this new service process model. Beyond Silos, and particularly the service process model that has been introduced, has allowed the delivery of integrated care at home with the support of ICT components (tele-assistance, telemonitoring of vital signs, online platform that includes the storage of critical social and health information) and also a complete new model of communication and interdependence between both departments of the services providers, but also external stakeholders (organisations, persons, services). This complete new service represents a huge gain of quality for: end users regarding security, quality of life, and comfort; organisations, through change management; and community, given that this model will boost the communication and interdependence between people and organisations, and between organisations.





## C.6 Sofia

	Health S.			So	ocial	S.	Т	hird	S.	Ot	her	pr.	PE	RSC	<b>N</b>	F/	AMI	LY		st	art	mid		fin	al
SOFIA	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final		n	%	n	%	n	%
HIth S	L	Н		L	Η		NA			NA			М	Н		М	Н		none		0		0		
Soc S	L	H		L	Μ		NA			NA			М	Н		М	H		low	8	67	0	0		
Third	NA			NA			NA			NA		NA NA							medium	4	33	1	8		
Other	NA			NA			NA			NA			NA			NA			high	0	0	11	92		
Pers	L	н		L	Н		NA			NA									added						
Fam	L	н		L	н		NA			NA															
																			n. tot. sco	res improv	/ed= 12/12				

Integration of health and social services was introduced in the legislation in Bulgaria only one year ago. As far as we know, there have been attempts to introduce it in practice in just a few municipalities. At national level, social care and healthcare are separate silos. For two years, BeyondSilos Sofia pilot has developed a platform and a model to integrate the social and health care for elderly persons with chronic diseases. The pilot has achieved high levels of integration with the support of ICT tools: telemonitoring, integrated health and social record, web portal and a database. Evidence shows that integration has improved, especially in the interaction of health and social care: "low" levels decreased from 67% to 0%. The degree of integration has reached "high" levels in 11/12 situations, thanks to the significant change from previous "low" and "medium" levels.





## C.6 Northern Ireland

	He	alth	S.	Sc	ocial	S.	T	hird	S.	Ot	her	pr.	PE		<b>N</b>	F/	AMI	LY		star	t	m	id	fir	nal
NIRE	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final	start	mid	final		n	%	n	%	n	%
HIth S	М	H		М	H		L	u		L	u		Н	a		М	а		none	4	13	4	13		
Soc S	М	а		М	н		L	u		L	u		Н	а		М	н		low	8	25	8	25		
Third	L	u		L	u		no	u		no	u		М	u		M u			medium	16	50	12	38		
Other	L	u		L	u		no	u		no	u		М	u		M u M u			high	4	13	8	25		
Pers	Н	а		Н	а		М	u		М	u								added*			8	25		
Fam	М	а		М	а		М	u		М	u		-						*added value	to 4 startiı	ng "hig	ıh" lev	el		
																			n. tot. score	improv	ed=12	/32 (3	8%)		

An improvement of integration in 12 (38%) of the total 32 possibilities were estimated. Because the integration utilises the NIECR, and this is currently only accessible to health and social care professionals, there is no expected impact on "Third" and "Other" sectors where current integration levels are "none" or "low". 25% of current "medium" impacts will improve to "high", with a further 25% remaining at "medium" but with the access to information giving "added value", and all of the current "high" levels will have "added value".

