Learning from integrated eCare practice and promoting deployment in European regions

BeyondSilos

D6.3 Final Outcomes

WP6 Pilot evaluation

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Document information

Organisation responsible

RSD

Authors

Daugbjerg, Signe (RSD)
Stafylas, Panos (HIM SL)
Da Col, Paolo (HIM SA)
Hurtado, Mayte (HIM SL)
Kubitschke, Lutz (empirica)
Müller, Sonja (empirica)

Contributing partners

Amadora deployment site
Badalona deployment site
Campania deployment site
Kinzigtal deployment site
Northern Ireland deployment site
Valencia deployment site
Sofia deployment site
Oates John (HIM SA)

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This deliverable contains original unpublished work except where clearly indicated otherwise.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

The overall aim of the BeyondSilos project was to optimise the care continuum for elderly care recipients with multiple co-morbidities and social needs by providing better integrated care (to overcome fragmentation between silos) which benefits from the support of ICT. It was hypothesised that the introduction of ICT supported integrated care would improve integrated care, and thus care recipients' perspectives, mainly emotional well-being, functional capability and satisfaction, while at the same time reduce their need for hospital admission and contacts with health and social care providers.. Another objective of the evaluation was to assess the economic and organisational impact of the new integrated service, and the social, ethical and legal aspects.

The BeyondSilos service was implemented and evaluated in seven European regions interested in employing ICT-based support for integrating healthcare, social care and self-care for different health / social conditions. The evaluation of the project was based on the seven domains in the MAST evaluation framework, adapted to fit the purpose of ICT supported integrated care. This report addresses the European added value of the project by combining the patient-level data from each pilot sites in order to identify common characteristics using valid statistical methodologies and other analysis methods. In order to overcome the differences in the local contexts, we have tried to identify possible common confounders, both at patient level as well as at site level. The methods are described in detail, and have been tested in other European projects, such as SmartCare and Renewing Health. To take into consideration the differences between deployment sites, local evaluations have been produces for each site; these have been included in the annexes.

From a final number of more than 10,000 service users, the evaluation cohort consisted of 973 care recipients with a mean age of 82 years old. The study population evaluated was found to be very homogeneous at a project level. However, some differences and diversities were discovered between the sites with regards to populations, services and outcomes. Overall, about 80% of the BeyondSilos population completed the follow-up period as planned. The integrated care (IC) group was followed for about 245 days' vs 206 days for the usual care (UC) group. From a clinical and technical point of view, the BeyondSilos services were safe to use for both care recipients and professionals, and there were no statistically significant differences in mortality. Regarding hospital admissions, no differences for total number of admissions to hospital or total number of days in hospital was found between the two care groups. The same trend was observed for unplanned hospital admissions.

More than 37,800 contacts with health and social care professionals were recorded. The analysis showed that receiving integrated care was associated with a higher annual contact rate with health and social care professionals.

The professionals involved in the project all agreed on that the new ICT supported service had a beneficial effect on the care provided. In all sites, the self-perceived level of integration improved as a result of the project. Furthermore, the sites reported that the new coordinated care had a positively impact on care recipients, who felt safer, better taken care of, and more in control of their own condition. However, the anticipated benefit of integrated care, in terms of less severe depression symptoms and better functional capability, have not materialised in the deployment sites. A more detailed discussion of key findings and conclusions can be found in section 9.

The majority of BeyondSilos services achieve an overall positive socio-economic return, meaning that overall service-related benefits outweigh overall service-related costs, including monetary, resource and intangible costs and benefits.

The BeyondSilos project focused on care recipients who, because of their advanced age and frail state, were in an elevated need of care; some were already in intensive care before the beginning of the project.

Given their advanced conditions at enrolment, it might be that any beneficial effect that ICT supported integrated care could have shown on the selected indicators, were obscured by the normal age-related deterioration associated with a population of frail older people. More research is therefore needed in order to identify proper measures of ICT supported integrated care in order to demonstrate the full advantages of the service, and for the EC and European citizens to take full benefit from the results of this project.

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1 Introduction

1.1 Purpose of document

This document presents the detailed outcomes and final project-level evaluation for the BeyondSilos project, as well as the site-level results.

The main characteristic of the project level evaluation is the diversity seen in each site and domain. Consequently, the project level evaluation is based on the deployment site level results, but efforts have been made to identify commonalities and differences among the different sites and services, and to try to produce evidence which could be useful for regions wishing to provide ICT-enabled integrated care. The complete description and results of the site level evaluations can be found in the annexes, while ~~in~~ this main document presents the project level evaluation.

1.2 Objective

The project objective is to identify relevant differences induced by implementing ICT-enabled integrated health and social care, mainly on the health and social care resources used, safety and clinical effectiveness, care recipients' perspectives and organisational aspects.

Any impact that ICT-supported integrated health and social care might have on all users is the subject of analyses according to the framework presented in the MAST model (Kidholm, et al., A model for assessment of telemedicine applications: MAST, 2012). The overall aim of MAST is to improve the possibilities for decision makers to choose the most appropriate care to be used in the most cost-effective way by providing a multidisciplinary assessment based on scientific methods and results.

MAST was adapted for BeyondSilos to cover aspects of social and healthcare integration; it includes the following domains:

1. Health and social situation of the care recipient and characteristics of service.
2. Safety.
3. Clinical and care aspects.
4. Care recipients' perspectives.
5. Economic aspects.
6. Organisational aspects.
7. Socio-cultural, ethical and legal aspects.

Deliverable D7.6 Deployment plans for BeyondSilos Pathways and Integration Infrastructure Final exploitation report underpins the evaluation with the economic aspects of the BeyondSilos integrated care services.

1.3 Background

The evaluation, at both project and site level, is based on the MAST evaluation framework, and the results are presented according to the MAST reporting guidelines. All sites were provided with guidelines on analyses, tables, and templates in order to present the results in a homogeneous way, despite the apparent differences in the population and the services under evaluation. Both joint and individual teleconferences were held between the evaluation team and the sites in order to assist them in preparing their results, and discuss how this should be done within the MAST framework.

Some of the deployment sites faced difficulties in collecting the required data on time and of the appropriate quality. Project and site level data quality control identified these issues, and partners invested additional time to resolve them. The project database hosted by Arsenal.IT closed at the beginning of January 2017.

Because of the extent of the evaluation, and in order for all the evidence produced to be available to anyone interested in providing ICT-enabled integrated care, there are a number of annexes that include all the local evaluation reports.

1.4 Structure of document

This deliverable is structured according to the MAST model; thus the chapters are:

- Chapter 2: Methodology: Describes the project population, primary research hypothesis, study design, indicators and outcomes, the completed tasks, and the statistical methods used.
- Chapter 3: Domain 1: Description of the health and social situation of care recipients.
- Chapter 4: Domains 2 & 3: Safety, clinical and care effectiveness.
- Chapter 5: Domain 4: Care recipients' perspectives.
- Chapter 6: Domain 5; Economic aspects.
- Chapter 7: Domain 6: Organisational aspects.
- Chapter 8: Domain 7: Socio-cultural, ethical and legal aspects.
- Chapter 9: Transferability.
- Chapter 10: Key findings and conclusions.
- Chapter 11: References.

The following appendices are included:

- Appendix A: Additional baseline and follow-up data
- Appendix B: Negative binomial regression analyses
- Appendix C: Interview guide for care recipients
- Appendix D: Interview guide for professionals

The following Annexes are attached:

- Annex 1 Final outcome for Badalona
- Annex 2 Final outcome for Kinzigtal
- Annex 3 Final outcome for Sofia
- Annex 4 Final outcome Valencia
- Annex 5 Final outcome for Northern Ireland
- Annex 6 Final outcome for Campania
- Annex 7 Final outcome for Amadora

1.5 Glossary

ADL	Activities of Daily Living
CR	Care Recipient
DoW	Description of Work
eCCIS	eCare Client Impact Survey
EHR	Electronic Health Record

GDS	Geriatric Depression Scale
GP	General Practitioner
HC	Health Care
HCP	Health Care Provider
IADL	Instrumental Activities of Daily Living
ICT	Information & Communication Technology
I/FC	Informal/Family Carer
PHC	Primary Health Care information system
PHR	Personal Health Record
SC	Social Care
SCP	Social Care Provider

2 Methodology

Interventions in the area of integrated eCare are in most cases complex interventions building upon a number of components that may act independently or interdependently, and involving and affecting a range of different stakeholders (Dyrvig, 2014). The project evaluated the functions and impacts of the BeyondSilos services from the point of view of the different principal roles / stakeholders, such as end users (care recipients), voluntary and informal carers, formal care staff / professionals, managers and fund-holders. Evaluation of integrated care service delivery processes will improve the current scientifically based knowledge on barriers and facilitators towards integrated care delivery. Beyond this, scientific knowledge will be generated on the outcomes of integrated care service delivery from the perspective of all actors involved.

2.1 Project population

The BeyondSilos service was implemented and evaluated in seven European regions interested in employing ICT-based support for integrating healthcare, social care and self-care for different health / social conditions, along integrated care pathways. The seven pilot sites were:

- Amadora.
- Badalona.
- Campania.
- Kinzigtal.
- Northern Ireland.
- Valencia.
- Sofia.

All settings that were in any way relevant to the provision of health and social care were included in the BeyondSilos project. Therefore, out-of-hospital (community) services as well as hospital departments, GPs' offices, community nurses, and any type of care practitioners, care recipients' homes and volunteer service providers’ offices were engaged in the project.

Together the sites have reported that more than 10,000 citizens have had the direct or indirect benefit of the BeyondSilos service, mainly due to the large number of citizens involved in Northern Ireland (Table 1). Based on information provided by local deployment site managers and local health authorities regarding this population, data have been collected from a representative sample of 973 care recipients (CRs) that comprised the evaluation cohort. In all, 165 healthcare professionals, 92 social care professionals, and more than 541 informal carers have been involved in the BeyondSilos project (Table 1). Their experiences of the project have been evaluated with qualitative methods, e.g. interviews. Data have been collected and reported in accordance with the BeyondSilos evaluation protocol (D6.1) and specific guidelines developed to assist in process evaluation and the reporting phase based on the MAST evaluation framework. All participants who fulfilled the eligibility criteria have been enrolled and evaluated.

Table 1: Final number of BeyondSilos services users

	Number of service users		Number of users evaluated		Healthcare professionals		Social Care professionals		Informal carers
Site	**Target**	**Current**	**Target**	**Current**	**Target**	**Current**	**Target**	**Current**	**Users**
Amadora	150	150	150	150	10	10	41	41	127
Badalona	200	200	200	199	20	20	36	36	237
Campania	100	100	100	100	102	102	5	5	97

Site	Number of service users		Number of users evaluated		Healthcare professionals		Social Care professionals		Informal carers
	Target	Current	Target	Current	Target	Current	Target	Current	Users
Kinzigtal	100	91	100	91	3-4	4	2	2	0
N.Ireland	10,000	>10,000	420	168	30	8	0	0	0
Sofia	100	100	100	100	6	6	3	3	30
Valencia	200	179	200	165	<15	<15	5	5	<50
TOTAL	10,850	>10,820	1270	973	187	165	92	92	<541

The size of the local evaluation cohorts were decided by each deployment site before the beginning of the project. The sample sizes were based on considerations regarding availability, budget, feasibility, etc.

Some deviations from the original plan of enrolment of 1,270 care recipients occurred, mainly because of difficulties experienced in recruiting participants for the project, delays in the start of local projects, or restrictions in the eligibility criteria decided in the evaluation protocol (D6.1).

In summary, the main reasons for deviation were:

- Northern Ireland: For the evaluation, initial indications were that 30 GP practices across N. Ireland could be recruited to evaluate 14 intervention patients and 14 control patients each (on average), giving a total of 420 intervention and 420 control in the evaluation. In reality, whilst 15 practices expressed a willingness to participate and attended workshops to help in the design of the SCS, at the end only eight practices agreed to collect patient data at the start of the evaluation and only four collected end data.
- Kinzigtal: There were five clients who were eligible, but their assigned GP did not participate in the BeyondSilos project, so they could not participate.
- Valencia: For the evaluation, the professionals found it very difficult to recruit care recipients. This was mainly because of scepticism from either the care recipients or their relatives who did not want their family member to participate. The restrictions in the eligibility criteria made it difficult to locate possible subjects, especially for the integrated care group.

The care recipients' evaluation cohort and the contribution of each deployment site to the overall BeyondSilos cohort are presented in domain 2&3, section 4.3.1.

As in the SmartCare project, the BeyondSilos pathways have been designed around two major service scenarios:

- Integrated long-term care support at home (ICP-LTCare pathway).
- Integrated care following hospital discharge (short-term) (ICP-SP or Discharge pathway).

Originally, it was planned that equal distribution of care recipients would be enrolled in the long-term pathway and in the short-term. Eventually, only one pilot site enrolled care recipients in the short-term pathway. In most sites, some form of eCare integrated services was already in place, so the majority of care recipients addressed were on a long term pathway. If they suffered an exacerbation, they would temporarily be moved to the short term pathway, but return to the long term pathway after recovery. For those enrolled on the short term pathway (hip fracture), the idea was to try to discharge to usual care, but because of age and frail state most continued on the long term pathway afterwards.

2.2 Primary research hypothesis for project level evaluation

The primary research hypothesis of the project was that BeyondSilos would improve care recipients' perspectives, mainly emotional well-being, social needs, and satisfaction, while at the same reducing their need for hospital admission and contacts with health and social care providers.

Another objective of the evaluation was to assess the economic and organisational impact of the new integrated services, and their acceptability by care recipients and professionals, and on the social, ethical and legal aspects.

2.3 Eligibility criteria

The eligibility criteria were decided among the sites and documented in the BeyondSilos Evaluation Protocol (D6.1) at the beginning of the project. They are as follows:

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 (ADL) 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 by the subject or if necessary 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, haves undergone an organ transplant, or are undergoing dialysis prior to enrolment.
- Subjects in a terminal state.
- People with an AIDS diagnosis.
- Within these inclusion criteria, the sites were free to select locally the population who would receive the local BeyondSilos services and who would be evaluated. Differences in health conditions and the services provided ended up producing an evaluation population with the characteristics as shown in Table 2.

Table 2: Commonalities and differences in the eligibility criteria among the different sites

	Amadora	Badalona	Campania	Kinzigtal	N. Ireland	Sofia	Valencia
Health / social care needs	Yes						
Able to use equipment	Yes	Yes	Yes	na	na	Yes	Yes
Signed consent	Yes				Only oral consent required	Yes	
Age	≥65y						
Heart Failure	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Diabetes Mellitus	Yes	Yes	Yes	Yes	Yes	Yes	Yes
COPD	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Fracture	Yes	Yes	No	No	Yes	Yes	Yes
Stroke	Yes	Yes	No	Yes	Yes	Yes	No

(na=not applicable)

2.4 Study design

The study design for the evaluation of BeyondSilos was a cohort-study (prospective observational study), meaning that groups of people with similar characteristics were followed over a period of time (Table 3).

In order to assess the effect of ICT supported integrated care, it was planned that all pilot sites should enrol care recipients in a ratio of 1:1 into two groups. One group would receive the new BeyondSilos care, and the other group would serve as a comparator group that would receive usual care. In most cases, the two groups ran in parallel. The only exception was:

- Amadora: From the beginning it was decided to involve 100% of the Home Care Support clients in the project; it was therefore not possible to enrol a parallel comparator group. Instead the study was planned as a "before-and-after" design, meaning that the care recipients exposed to the new service served at an earlier time as their own comparator. The control period began eight months before the new BeyondSilos treatment was introduced, and the intervention period began when the new BeyondSilos treatment was introduced. Information for the control period was collected historically.

The rules of allocation of care recipients into care groups differed between sites (Table 3). Most often, randomisation for allocation was used; one used geographical aspects to decide the groups, while another left it to the discretion of the involved GPs to ensure a balance of care recipients in each group.

All sites tried to ensure that the two care groups compared were as similar as possible in order to avoid introducing confounding factors in the analyses. However, in some cases, the number of care recipients recruited and the allocation methods used seemed to reflect the difficulties experienced in recruiting participants to reach the target set out in the DoW.

Table 3: Study design

	Amadora	**Badalona**	**Campania**	**Kinzigtal**	**N. Ireland**	**Sofia**	**Valencia**
Study design	Observational						
Intervention	Prospective						
Comparator	Historic	Prospective					
Allocation ratio	1:1	1:1	1:1	1:1	1:1	1:1	1:1
Randomisation	No	Yes	Yes	Geographic control group	No	Yes	Yes*

* First care recipients enrolled were matched by sex and age when allocated to care group. However due to difficulties in enrolling participants, especially to the integrated care group, the allocation method was changed to randomisation.

2.4.1 Primary project-level outcome

The overall aim of the BeyondSilos project was to optimise the care continuum for elderly care recipients with multiple co-morbidities and social needs by providing better integrated care (to overcome fragmentation between silos) which benefits from the support of ICT. It was hypothesised that the introduction of ICT supported integrated care would improve integrated care, and thus care recipients' perspectives, mainly emotional well-being, functional capability and satisfaction, while at the same time reducing their need for hospital admission and contacts with health and social care providers.

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

The effect of introducing ICT supported integrated care for care recipients with multiple co-morbidities and social needs was examined by comparing:

- Difference in number of admissions.
- Difference in numbers and types of contacts with health and social care providers.
- Differences in mortality rates.
- Difference in functional capability for activities of daily living (Barthel & IADL scales) and emotional well-being (Geriatric Depression Scale).
- Difference in care recipient's satisfaction.
- Differences in costs.
- Differences in organisational aspects caused by implementing ICT supported integrated care.

2.4.2 Data collection sources

Most sites had to collect data through either interviews or questionnaires conducted by professionals doing recruitment and follow-up. Only one site could rely mostly on data collected from Electronic Healthcare Records complemented with some information gathered by questionnaires. Standardised questionnaires translated into the relevant languages were used by all sites to collect data regarding the Geriatric Depression Scale, the Instrumental Activities of Daily Living scale, and the Barthel scale. Questionnaires regarding eCCIS and PIRU were provided by the evaluation team in English, and translated if necessary by the sites. The collection method and data sources regarding the data collection varied among sites, see Table 4 below.

Table 4: Data Sources and collection procedures

	Data source						
Variable	**Amadora**	**Badalona**	**Campania**	**Kinzigtal**	**Northern Ireland**	**Sofia**	**Valencia**
Enrolment	Questionnaire provided by the Project	Electronic Health Record	LHA list of patients in ADI service	Mainly by patient record, partly by interviews	GP patient record and interview with patient.	Questionnaires	Hospital databases and clinical measurements
GDS	Questionnaire provided by the Project	Electronic Health Record	Nurse interview	Results of assessments via questionnaires	Interview with patient	Questionnaires	Questionnaire
PIRU	Questionnaire provided by the Project	Purpose designed questionnaire	Nurse interview	Interview with patient	Interview with patient	Questionnaires	Questionnaire
Barthel	Questionnaire provided by the Project	Electronic Health Record	Nurse interview	Results of assessments via questionnaires	Interview with patient	Questionnaires	Questionnaire
iADL	Questionnaire provided by the Project	Purpose designed questionnaire	Nurse interview	Results of assessments via questionnaires	Interview with patient	Questionnaires	Questionnaire
Use of care services	Questionnaire provided by the Project	Electronic Health Record	Nurse interview		From data in GP system and NIECR.	Questionnaires	Questionnaire
Social Support	Questionnaire provided by the Project	Electronic Health Record	Social worker interview		From data in GP system and NIECR.	Questionnaires	Interview
eCCIS	Questionnaire provided by the Project	Purpose designed questionnaire	Nurse interview	Data collected via interviews between project manager and professionals	Interview with patient	Questionnaires	Questionnaire
Care recipients' experience	Interviews	Interviews	Interviews	Interviews	Interviews	Interviews	Interviews
Professionals' experience	Interviews	Interviews	Interviews	Interviews	Interviews	Interviews	Interviews

2.5 Methodological considerations

The analyses were based on information collected by each site and uploaded to the central database of Arsenal.IT. Guidelines were distributed and meetings were held regarding data collection methods and analysis. All results were processed and analysed by a group of statistical experts; this was the same for all analyses, both at project level and at deployment site level. This homogeneous approach to handling data secured uniformity in the analyses, and all analyses were performed to the same high standard. From the beginning of the BeyondSilos project, it was agreed in the evaluation protocol (D6.1) to collect a large number of different individual parameters on demographic characteristics, socioeconomic variables, clinical conditions, lifestyle factors, technical literacy, social needs and care utilisation, which made it possible to compare and describe the two care groups in detail and perform confounder adjusted analyses. Each site also drafted a local operational protocol based on the evaluation framework. These can be viewed in the annexes to deliverable D6.1 Evaluation Framework. Some methodological strengths and weaknesses in the analyses presented should be considered when interpreting the results and their implications.

2.5.1 Study population

Based on information provided by local deployment site managers and local health authorities regarding the study population, it is assumed that the BeyondSilos population is somewhat representative of the overall population of care recipients with similar needs. However, due to the relatively small sample size enrolled, it cannot be ruled out that a potential source of bias in the selection of the study population has occurred. This is especially the case in the allocation of care recipients to the two care groups in sites where randomisation was not used.

2.5.2 Measurement error and missing values

The origin of the data collected and used for the analyses varied between sites. Most sites had to collect data manually, either through interviews or questionnaires conducted by professionals doing recruitment and follow-up which might introduce reporting errors. Only one site was able to rely mostly on data collected from electronic health records, supplemented with some information gathered by questionnaires. However, only if the possible reporting errors were more present in one care group than the other might this have affected our results.

The possibility of inadvertently introducing errors due to lack of thorough training of the professionals when gathering measurements (as interviewers or observers) has been raised with the sites. Some of the sites faced unexpected difficulties in collecting all the data and questionnaires described in the evaluation protocol. This has affected the size of the common dataset that has been available for the project level analysis. It cannot be ruled out that missing values for some of the collected variables, especially for the comparator group (usual care), might have affected the results.

2.5.3 Confounding

Although quite substantial adjustments were performed in the analyses, the limit of information available, the sample size, the number of missing values, and the quality of data uploaded in the central database sets a natural limitation to the confounder adjustments. Unmeasured or poorly measured variables, as well as poorly performed randomisation, would introduce residual confounding in the analyses. For example, unmeasured confounding from genetic or family related factors, cognitive function, social isolation and general vulnerability might influence some of the outcome measures, such as: the type and frequency of contacts with health and social care, functional capability, and emotional well-being, which may have led residual confounding to be a potential source of error in the analyses.

2.5.4 Statistical models

Considerable efforts were put into data cleaning and removal of outliers, and numerous of Skype meetings took place between the sites, the statistical team, and the evaluation team, in order to have the most complete dataset with the best data quality possible to use for the analyses. All statistical analyses, from the descriptive statistics to the regression analyses, were performed using well-known standardised procedures described in detail below.

2.6 Statistical methods

The statistical analysis of the data collected by the deployment sites was performed by the same team who successfully completed the statistical analysis for the SmartCare project. The methodology was almost the same, but with minor modifications to fully comply with the needs of this specific dataset, e.g. the BeyondSilos data were much more homogeneous than SmartCare, consequently a number of adjustments and subgroup analyses were not relevant, and the results have the potential to be more robust.

2.6.1 Assessing normality

Since normality is one of the assumptions for many of the statistical tests that were conducted, normality plots were used and interpreted as follows:

- Histograms; if data are normally distributed, then the curve is bell-shaped.
- Boxplots; if data are normally distributed, then the median (black line) is in the middle of the box.
- Normal Q-Q plots; if data are normally distributed, then the points form a line.

Tests also assess the normality of distributions of variables:

- Shapiro-Wilk test is used for sample sizes less than 50.
- Kolmogorov-Smirnov test is used for sample sizes more than 50.

If p-values are less than 0.05, then data are not normally distributed.

2.6.2 Descriptive statistics

Descriptive statistics are used:

- to describe the characteristics of every site population;
- to address specific research questions;
- to check variables for any violation of the assumptions underlying the statistical techniques used (Pallant, SPSS Survival Manual. A step by step guide to data analysis using SPSS, 5th edition, 2013).

Descriptive statistics also provide some information concerning the distribution of continuous variables (skewness and kurtosis).

- **Continuous variables (quantitative):** All continuous variables are presented as numbers of patients per patient group (intervention, comparator) having this characteristic and percentages (n, %). Continuous variables are compared between two groups by t-test or between three (or more) groups by Analysis of Variance (ANOVA) test, when normally distributed, and by Mann-Whitney U-test or Kruskal-Wallis test, respectively, if non-normally distributed. All p-values less than 0.05 are considered statistically significant.

- **Categorical variables (qualitative):** All categorical variables are reported as means and standard deviations (SD) per patient group (intervention, comparator). Categorical variables are compared by the Chi-square (X^2) test, and the statistical significance is assessed by Pearson's correlation coefficient. All p-values less than 0.05 are considered statistically significant.

Several clinical outcomes can be expressed as absolute and relative (delta, %) differences between intervention and comparator group.

The Table below describes analytically all possible kind of analyses to carry out, based on type and distribution of variables (Hair, Black, Babin, Anderson, & Tatham, 2006)

Table 5: Matrix of analyses (comparing groups)

Independent variable	Dependent variable	Parametric statistic	Non-parametric statistic	Essential feature
One dichotomous	One dichotomous	None	Chi-square	Identifies number of people in each category
One dichotomous	One continuous	Paired samples t-test	Wilcoxon Signed-Rank test	Same people on two different occasions
One dichotomous	One continuous	Independent samples t-test	Mann-Whitney test	different samples

2.6.3 Regression analyses

Regression analyses are used to assess the primary and secondary outcomes of the project. After removing outliers, we estimate the adjusted differences between the intervention and the comparator group, and determine the effect of several variables on primary and secondary outcomes. In order to perform multiple linear regression analysis, we check if the following assumptions hold (Cohen, Cohen, West, & Aiken, 2003):

- Normality: the errors should be normally distributed; technically, normality is necessary only for the t-tests to be valid, estimation of the coefficients only requires that the errors be identically and independently distributed.
- Linearity: the relationships between the predictors and the outcome variable should be linear.
- Homogeneity of variance (homoscedasticity): the error variance should be constant.
- Independence: the errors associated with one observation are not correlated with the errors of any other observation.
- Model specification: the model should be properly specified (including all relevant variables, and excluding irrelevant variables).

Before running regression analyses, the skewed data was transformed (square root, reflect and square root, logarithm, reflect and logarithm, square, inverse, and reflect and inverse), until we found the transformation that produces the skewness and kurtosis values nearest zero, the prettiest picture, and/or the fewest outliers (Tabachnick & Fidell, 2013) (Allison, 1998). The type of regressions depends on the number of non-zero values of the primary and secondary outcomes. (Freund & William, 1997), (Greene W. , 1990), (Johnson, 1994), (Myers R. H., 1990), (McNamee, 2005 Jul; 62(7)).

If the number of zero values was bigger than 70%, then we conducted logistic regression analysis, by transforming the continuous dependent variable to a discrete variable, where 0 stands for zero values and 1 stands for all the other values (Agresti, 2002), (Hosmer, Lemeshow, & Sturdivant, 2013). Multicollinearity was detected by examining the tolerance for each independent variable, where tolerance values less than 0.10 indicate collinearity. The Hosmer & Lemeshow test was used to determine the goodness of fit of the logistic regression models.

There are many possible distribution-link function combinations (SPSS Advanced Statistics 17.0, 2007), and several may be appropriate for our given dataset. Hence, our choice was guided by a priori theoretical considerations on which combination seemed to fit best. The most common analyses were:

- **Gamma.** This distribution is appropriate for variables with positive scale values that are skewed toward larger positive values. If a data value is less than or equal to 0 or is missing, then the corresponding case is not used in the analysis.
- **Inverse Gaussian.** This distribution is appropriate for variables with positive scale values that are skewed toward larger positive values. If a data value is less than or equal to 0 or is missing, then the corresponding case is not used in the analysis.
- **Poisson.** This distribution can be thought of as the number of occurrences of an event of interest in a fixed period of time, and is appropriate for variables with non-negative integer values. If a data value is non-integer, less than 0, or missing, then the corresponding case is not used in the analysis.
- **Negative binomial.** This distribution can be used for over-dispersed count data, that is when the conditional variance exceeds the conditional mean. It can be considered as a generalisation of Poisson regression, since it has the same mean structure and it has an extra parameter to model the over-dispersion. If the conditional distribution of the outcome variable is over-dispersed, the confidence intervals for the negative binomial regression are likely to be narrower as compared to those from a Poisson regression model.

3 Domain 1: Health and social situation of the care recipients and characteristics of the service

3.1 Introduction

The first domain includes a description of the health and social situation of the care recipients and of the care being offered. This includes a description of the health and social needs of the care recipients, a summary of the ICT solution for integrated care, including technical characteristics and the requirements for use, (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 evaluation has been carried out, and helps to understand the perspective from which the assessment has been performed.

At the start of the project, the sites agreed to enrol care recipients with the presence of one of the following conditions as their main disease: heart failure, stroke, COPD, fractures or diabetes. An important additional inclusion criterion for the BeyondSilos project was the presence of social needs. Therefore domain 1 begins with a general description of the diseases and of social needs.

3.2 Summary points on 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 burden of disease, please see “The global burden of disease: 2004” issued by the World Health Organisation[1].

3.2.1 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.

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[1] http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/

The 2011 update of the GOLD guidelines[2] 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.

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 exposure 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 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[3]. 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[4].

3.2.2 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 led by many people, it is estimated that an enormously increased number of people will suffer from the disease in the future.

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[2] 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

[3] 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/

4 Murray CJ, Lopez AD. Measuring the global burden of disease. N Engl J Med. 2013;369(5):448-57

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[5]. Since most of the care recipients enrolled in the BeyondSilos project because of a diabetes diagnosis suffer from type 2 diabetes, the following description focuses on this type.

Diabetes mellitus type 2 is a metabolic disease characterised by insulin resistance due to multifactorial factors. 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 preceded by an asymptomatic phase of about seven years[6], during which hyperglycaemia causes deleterious effects at target tissue level, so that at the moment of clinical diagnosis the complications of the disease are already present.

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)6.

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 ≥ 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[7].

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%[8].

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[5] WHO 2012

[6] “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

[7] http://www.idf.org/guidelines-older-people-type-2-diabetes

[8] Rossana de Lorenzi, Cristina Gritti, “Verso il primo farmaco ricombinante”, European Molecular Biology Laboratory 2007

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^2), 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).

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.

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[9].

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[10].

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[9] International Diabetes Federation Data - 2010

[10] http://changingdiabetesbarometer.com/docs/Diabetes%20den%20skjutle%20epidemic%20og%20konsekvenserne%20for%20Danmark.pdf

3.2.3 Cardiovascular diseases (CVDs)

Cardiovascular diseases are the largest cause of deaths worldwide[11]. 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[12]. 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.

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.

3.2.4 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% are 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 (hemianopia), 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, treatment is focused on revascularisation (thrombolysis), cardiovascular control, such as hypertension, and metabolic control (hyperglycaemia-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 mid-term 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 extent and kind of stroke, age, functional independence at discharge, the comorbidities, but also on the rehabilitation programme and social support[13]. The prevention of recurrences is the other main goal of therapy, which can be obtained by controlling risk factors (primarily hypertension).

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[11] 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)

[12] 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)

[13] Factors predictive of stroke outcome in a rehabilitation setting. Ween JE, Alexander MP, D'Esposito M, Roberts M. Neurology 1996; 47(2): 388-92

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[14].

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[15]. The estimated cost in Europe in 2010 was roughly 64.1 billion €[16]. 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.) and the social consequences, mostly due to disability, also to anxiety, depression, social isolation, require intensive interventions in this group of patients[17].

3.2.5 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.

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[14] 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)

[15] 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.

[16] Gustavsson A, Svensson M, Jacobi F, et al. Cost of disorders of the brain in Europe 2010. Eur Neurpsychopharmacol 2011;21:718-779.

[17] 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.

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[18].

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[19].

At any age, hip fracture is approximately twice as common in women as in men[20]. 90% of cases occur in people over 50 years old, rising in incidence dramatically with increasing age[21]. In this context, hip fracture is associated with significant morbidity and mortality (20-24% in the first year after discharge)[22]. Loss of function is important with 40% of cases unable to walk independently after one year of follow-up[23]. 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.

3.3 Summary points on 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).

3.3.1 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.

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[18] Cooper C, Campion G, melton III LJ. Hip fractures in the elderly: a world-wide projection. Osteoporosis Int 1992;2:285.

[19] 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.

[20] Jacobsen SJ, Goldberg J, Miles TP, et al. Hip fracture inci- dence among the old and very old: a population-based study of 745,435 cases. Am J Public Health 1990;80:871-3

[21] Cumming RG, Nevitt MC, Cummings SR. Epidemiology of hip fractures. Epidemiol Rev 1997; 19(2): 244-257

[22] 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.

[23] 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.

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 full 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 of Daily Living)[24].
2. The performance in activities of daily living measured by the Barthel scale[25].
3. Measurement of actually social care provided to each care recipient, though this does not necessarily correspond to what they actually need[26].

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 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, GP 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[24]. 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.

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[24] 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.

[25] Mahoney FI, Barthel D. “Functional evaluation: the Barthel Index.” Maryland State Medical Journal 1965;14:56-61

[26] See Appendix A.

3.4 General description of the current management of the health and social situation (including integration level)

In Annexes 1-7, each of the pilot sites has described the current management (before BeyondSilos) of the health and social situation of the care recipients. This includes a description of the social and health assistance available, and which integrated services, if any, are being offered to the care recipients.

To give a clear overview of the current management and the interaction between actors / sectors before the new BeyondSilos service was introduced, each pilot site has produced a table reporting a self-assessment of the integration within and between the main care actors, scoring qualitatively the degree of interactions (from “none” to “low-medium-high” scores). In these tables, a short description of the current, if any, integrated care is given; a description of the new services and what these add is also included. In relation to the definition of care providers (actors), they were identified as belonging to six primary categories: health and social institutions responsible for home care delivery; third sector or independent providers; care recipient and her/his family or friends. In Domain 6, the pilot sites have updated this qualitative assessment by scoring the changes in integration quantitatively using a methodology developed for this purpose. For a further description of the care provider categories and the quantitative scoring system, please refer to Domain 6, where the general issue of integration and integrated care is dealt with in depth, since these are mainly organisational aspects. The specific information for each site (Usual care vs New care Matrix) is reported in the individual site annexes, Annexes 1 - 7.

Table 5 summarises the main results across sites regarding current management and the interaction between actors / sectors. It reports only the most evident characteristics of the usual care provided before introducing the new BeyondSilos treatment, as reported by professionals of the health and social services in the seven sites.

In summary, these descriptions, which depict an “average” opinion drawn from several assessments coming from all sites, highlight that the main level of integrated services being offered in the usual service varies across sites. Some pilot sites are already sharing and facilitating some information / data exchange between actors, while others have no formal agreements, and interaction is more random or accidental. It seems that some participation and involvement of both the care recipients and the family / care givers is occurring, but mostly by request.

Table 5: Cross-site summary of Usual Care Matrices

	Health services	Social services	Person- care recipient	Family –entourage
Health services				
Usual care	There are relations between different levels of healthcare provided, but there are no common databases and formal agreements. Because of the nature of the organisation which includes the three classic healthcare levels, clear workflows are defined and ICT solutions are fully integrated. GPs and specialists relate occasionally. Established central electronic patient record for GPs and specialists. Some information is available in the shared care platform. Multiple systems in use by different professionals. No single summary view available. There are relations between different levels of healthcare provided, but there are no common databases and formal agreements.	There are no social services in routine use for care recipients. Social services and health services are in different silos. Any interaction is accidental. Clear workflows defined and ICT solutions fully integrated. Case Managers in every centre and any healthcare level. Communication via phone call, telefax or personal contact. Usually there is more information requested from social care to health care than the other way round. Referrals by GPs, other HCPs and self-referral. HCPs have no sight of social systems. Paper based and time consuming information flows.	Case management care through telemedicine. The patient has constant access to his GP and specialist, if needed. 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. Practice visits, phone calls or home visits. Interaction with practice assistance is sometimes higher than short treatment time in front of physician. HCP view of CR info is fairly narrow / profession centric. None or limited view of other HCP/SCP information about CR.	Support for patient management through telemedicine. The family members can discuss the disease of their relatives at their request. Interaction only in case patient wants to; he is the interface between both. Amount of interaction with family / entourage varies from case to case. The family members can discuss the disease of their relatives at their request.

	Health services	Social services	Person- care recipient	Family –entourage
Social services				
Usual care	There are no social services in routine use for caring for CMCP users. Social services and health services are in different silos. Any interaction is accidental. Because of the nature of the organisation, clear workflows defined and ICT solutions fully integrated. Case Managers in every centre and any healthcare level. 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 healthcare provider. Referrals by GPs, other HCPs and self-referral. SCP has no sight of HCP systems. Paper based and time consuming information flows.	Social services could be provided by regional government in some cases, and hired from a private company in others. Social services are provided in a bureaucratic and formal manner. Because of the nature of the organisation. Clear workflows defined and ICT solutions fully integrated. Interaction within institution via meetings, common documentation system. SCP can share information in social care system with appropriate access controls (used mostly for team working to cover absence).	Only when the care recipient hires these services, or assigned by the Municipality. Care recipients receive social services from different agencies with little interaction between them. 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. Patients receive assistance according to integrated plan. Visits by ambulant nurse and phone calls, consultancy meetings. CR tends to interact with one named SCP only.	Family members are barely involved in the planning of social care. 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. Support for relatives in assisting patients. Interaction is in a 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. Amount of interaction with family / entourage varies from case to case.

3.5 Description of the ICT solution supporting integrated care (including technical characteristics and requirements for use)

The aim of BeyondSilos was to develop and pilot integrated care services delivered with the help of a multifunctional ICT infrastructure. The technical solutions used in BeyondSilos are based on state-of-the-art technology. A large subset of these have been independently tested and installed as fully functioning solutions in commercial projects and in large scale pilots. However, the same set of services has never been combined before in a single comprehensive solution. The technological platforms procured for BeyondSilos have been integrated independently in each of the sites within their current ICT infrastructure due to the differences in these infrastructures. The number and complexity of components being implemented for the BeyondSilos project differs between sites, from some regions integrating the electronic health and social records to others also including triage systems, systems to help patient data management, decision support and scheduling, telecare communication, training platform, behaviour monitoring, vital sign monitoring, ambient monitoring, remote device administration, emergency communication, and personal data protection. Table 6 below shows the core building blocks of the ICT solutions for each pilot site. The table describes both the ICT solutions available prior to BeyondSilos, and the ones developed and implemented for the project.

Table 6: ICT building blocks available before BeyondSilos and developed for BeyondSilos for each site

ICT-based core integration building blocks	Main components	Northern Ireland		Sofia		Badalona		Valencia		Campania		Amadora		Kinzigtal	
A=Available before BeyondSilos; N=New in the project		A	N	A	N	A	N	A	N	A	N	A	N	A	N
Triage	List of patients.	X			X	X		X		X		X	X	X	
	Search and follow up of patients.	X			X	X		X		X			X	X	
	Triage report	X				X		X		X				X	
	Patient form	X			X	X		X		X		X	X	X	
	Triage process	X				X		X		X				X	
Data Management	Patient master index	X			X	X		X		X		X	X	X	
	Admission	X			X	X		X		X		X	X	X	
	Inpatient management	X				X		X		X			X	X	
	Outpatient management	X			X	X		X		X			X	X	
	Emergency management	X			X	X		X		X		X	X	X	
	Theatre management	X						X		X				X	
	Waiting list management	X				X		X		X					
	Inpatient billing	X				X		X		X				X	
	Reporting	X			X	X		X		X			X	X	
	Compliance	X		X	X	X		X		X					
Workflow / Decision Support	Computerised alerts and reminder	X		X	X	X		X			A	X	X	X	
	Clinical guidelines			X	X	X		X			A			X	
	Condition-specific order sets					X		X		X		X	X	X	
	Documentation templates		X(SCP)			X		X		X			X	X	
	Diagnostic support, contextually relevant references to information			X	X	X		X		X				X	
	Focused patient data reports and summaries	X		X	X	X		X		X			X	X	

ICT-based core integration building blocks	Main components	Northern Ireland		Sofia		Badalona		Valencia		Campania		Amadora		Kinzigtal	
A=Available before BeyondSilos; N=New in the project		A	N	A	N	A	N	A	N	A	N	A	N	A	N
Scheduling	Calendar			X	X	X		X		X		X	X	X	
	Address book			X		X		X		X		X	X	X	
	Appointment calendar				X	X			X	X		X	X	X	
	Appointment reminders			X		X			X	X		X	X	X	
	Appointment attachments				X	X			X	X			X		
Telecare Communication	videoconferencing			X	X								X		
Questionnaires						X			X	X		X	X	X	
Learning / Training platform	Videoconferencing				X							X	X		
	Document reader				X							X	X		
Tele-rehabilitation	Videoconferencing module			X											
	Sensors and body monitoring			X											
	Connection with EH&SR			X		X									
Behaviour Monitoring	sensor network				X	X									
	Reasoning					X									
Vital Sign Monitoring	Sensors and devices	X		X	X		X		X		X	X	X		
	Local data storage at patient's site	X		X	X		X		X		X				
	Connection with the centralised EH&SR data repository		X	X	X		X		X		X	X	X		
Ambient monitoring	Environmental sensors that measure ambient parameters	X		X	X							X			
	Home automation actuators											X			
	Local data storage at patient's site			X	X										
	Connection with EH&SR		X	X	X							X			
Remote Device Administration	Device manager	X		X	X	X			X		X	X	X		

ICT-based core integration building blocks	**Main components**	**Northern Ireland**		**Sofia**		**Badalona**		**Valencia**		**Campania**		**Amadora**		**Kinzigtal**	
A=Available before BeyondSilos; N=New in the project		**A**	**N**	**A**	**N**	**A**	**N**	**A**	**N**	**A**	**N**	**A**	**N**	**A**	**N**
Third party services	Interface systems					X			X		X				
Alerts Management	Multimodal alert system	X		X	X		X		X		X	X	X		
Contact Centre	Health intervention module	X		X	X	X		X				X	X	X	
	Social intervention module	X		X	X	X			X					X	
Emergency Communication	Multichannel communication	X		X	X	X		X		X		X	X		
Electronic Health and Social Record	Medical data		X (TNI)	X	X	X		X		X		X	X	X	
	Social Data		X (eNISAT)	X	X	X			X					X	
	Digital interoperability		X			X			X						X
	Care & outcomes tracking	X				X		X							X
	Reporting	X	X(SCP)	X	X	X		X				X	X		X
Predictive Modelling	Assessment and adjustment of risk behaviour						X		X						
Personal Data Protection	Secure Data layer	X		X	X	X		X		X		X	X	X	
	Communication protections	X		X	X	X		X		X		X	X	X	
	Access policies	X		X	X	X		X		X		X	X		X
	Secure access	X		X	X	X		X		X		X	X		X
	Log & auditing module	X		X	X	X		X		X		X	X	X	

Due to the difference in the complexity of the components being implemented and their technical characteristics, the training level of end users also varied across regions. However, in general a great focus has been given to training all end-users both at the start of the service and when needed through workshops, training from key staff members and implementation of helpdesks. The deployment sites have described the technical characteristics and requirements for use of their individual ICT solutions in Annexes 1-7.

To clarify the main set of ICT building blocks in the BeyondSilos architecture, the diagrams below show the integration infrastructure for each of the pilot sites. Green squares indicate the existing components used in the usual treatment, the red squares indicate a new component for the treatment, and the yellow squares indicate an improvement of an existing component.

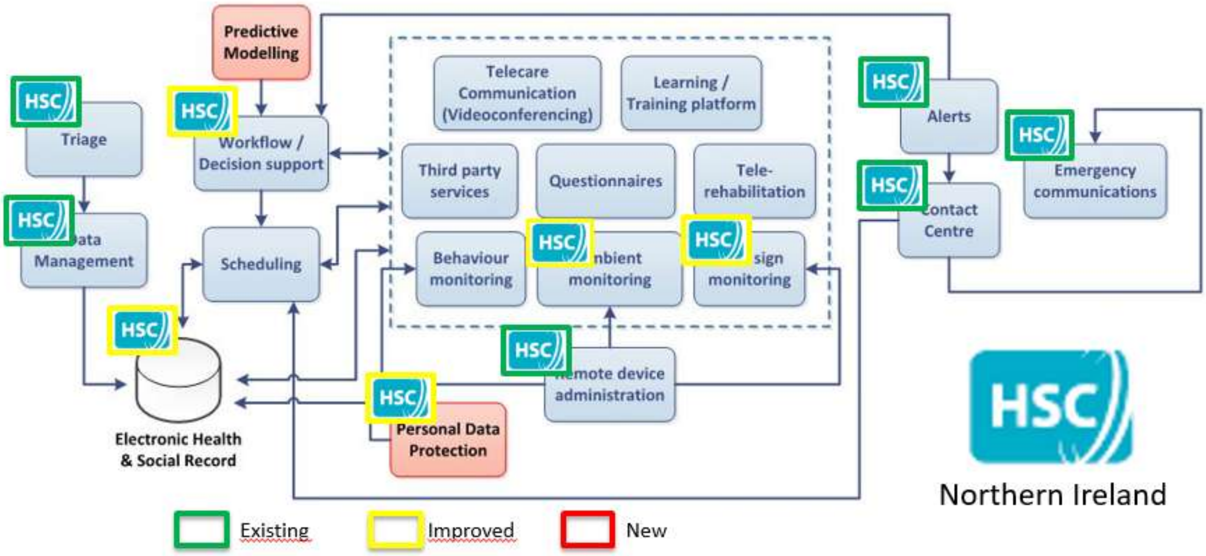


Figure 1: Northern Ireland building blocks

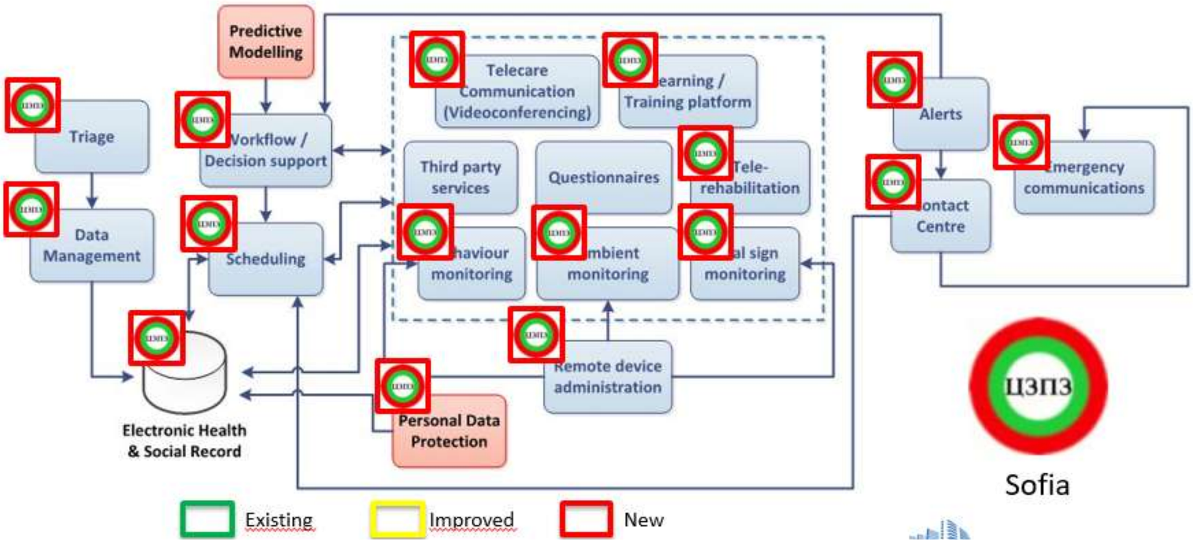


Figure 2: Sofia building blocks

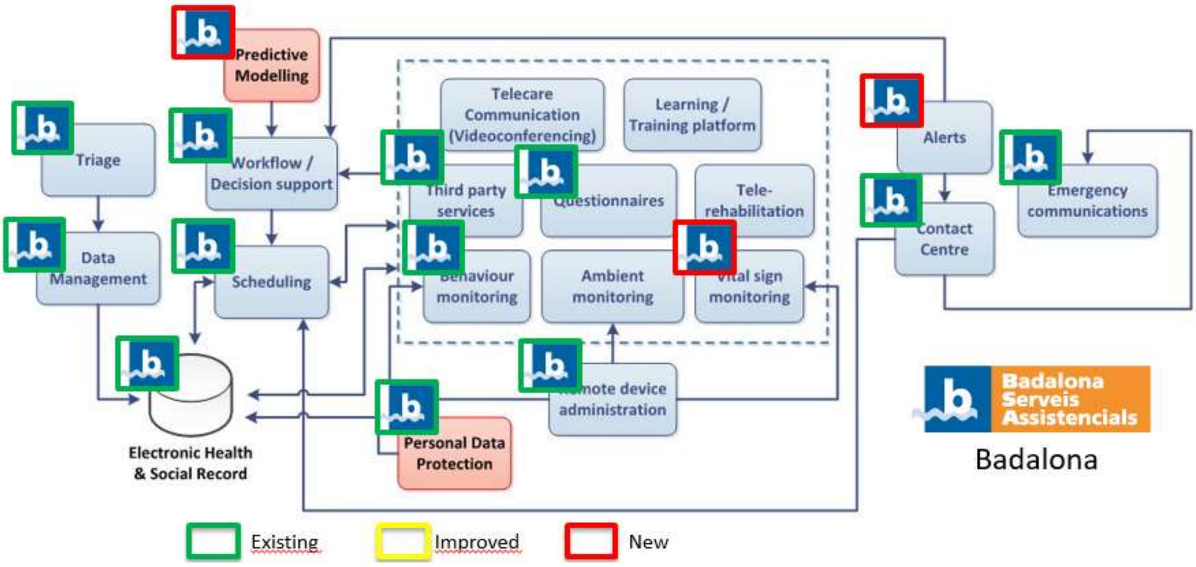


Figure 3: Badalona building blocks

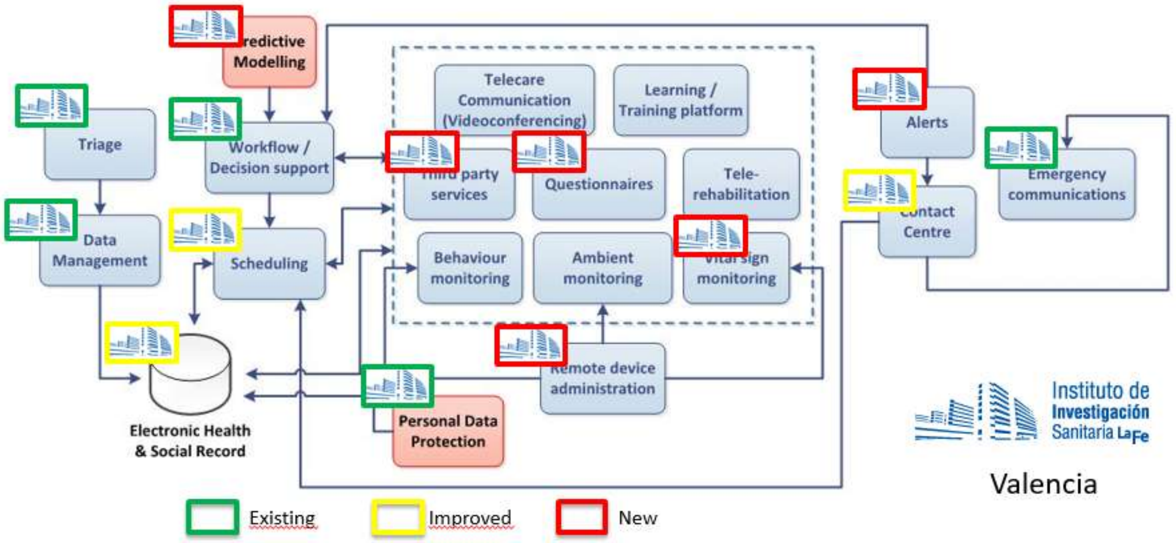


Figure 4: Valencia building blocks

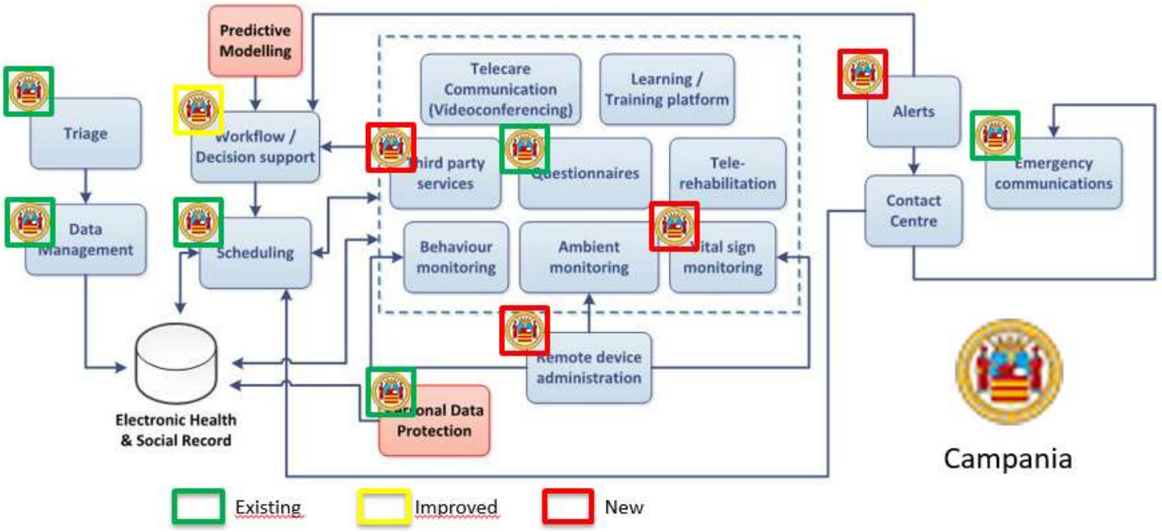


Figure 5: Campania building blocks

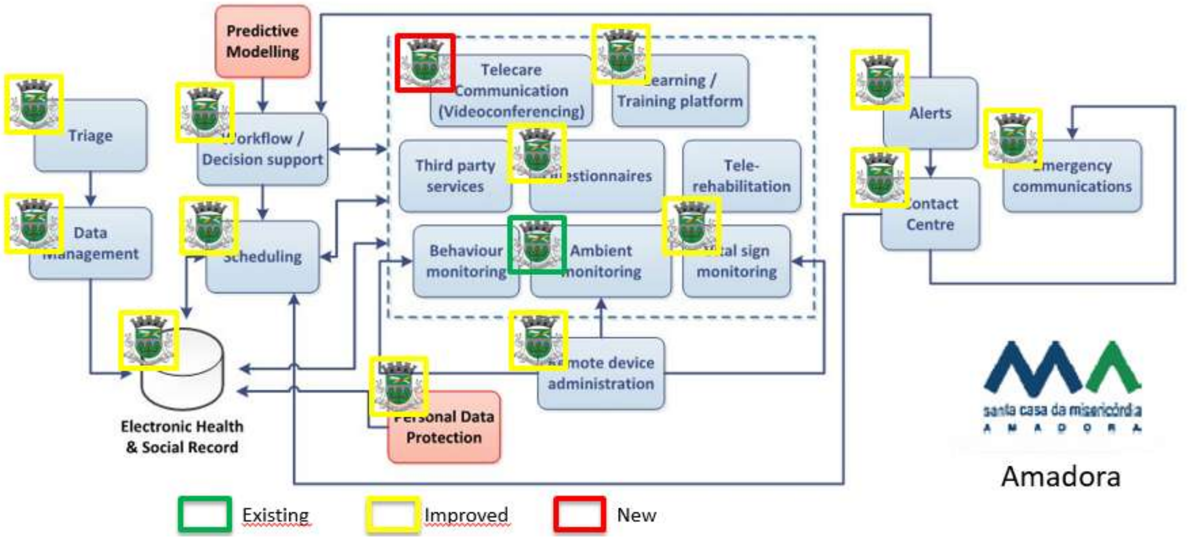


Figure 6: Amadora building blocks

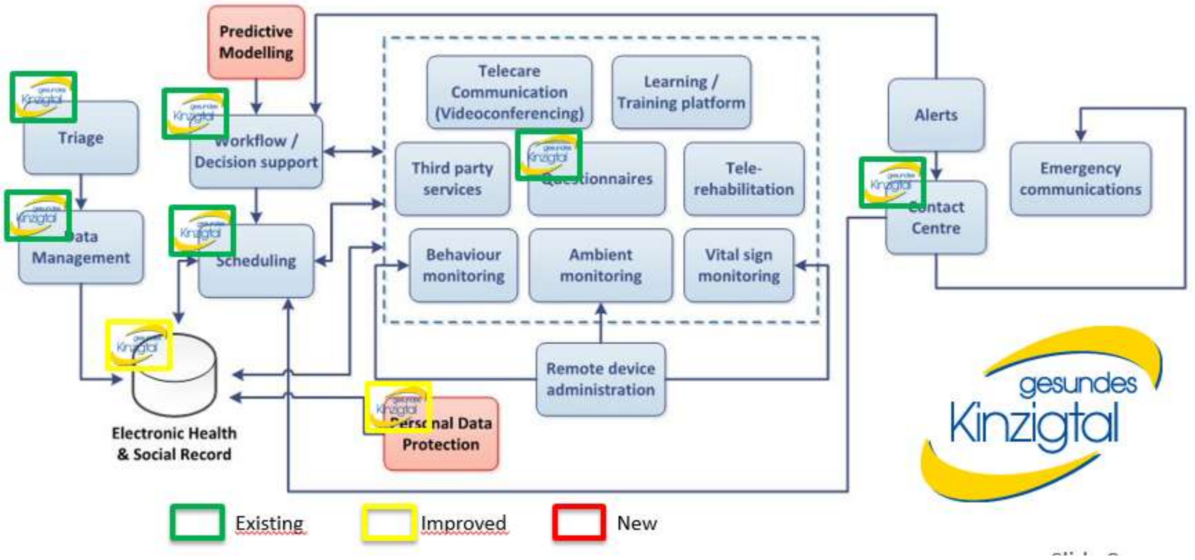


Figure 7: Kinzigtal building blocks

3.6 Key lessons learned

- 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).
- The main level of integrated services that was being offered before the BeyondSilos service was introduced varied across sites. Some pilot sites were already sharing and facilitating some information / data exchange between actors, while others had no formal agreements and interaction occurred more randomly or accidentally.
- Participation and involvement of both the care recipients and the family / care givers was occurring, but mostly only by request.
- By deploying the BeyondSilos service, all seven sites are now devoting more specific attention to improving home care services, placing them as a priority for the new organisation of innovative and

valuable care settings for long-term conditions. This is particularly true for heart failure, but also for diabetes, COPD, stroke and fractures, especially when associated with social needs. We have learned that these “new” home care services may need to be tailored to meet complex needs, i.e. the coexistence of health problems and compromised capacities in performing basic daily activities, a very frequent occurrence in old age. This integrated approach (whole life approach) is the only one that can guarantee success even for the health aspects (medical disease treatment).

- The technical solutions used in BeyondSilos are based on state-of-the-art technology. A large subset of these have been independently tested and installed as fully functioning solutions in commercial projects and in large scale pilots.
- The technological platforms procured for BeyondSilos have been integrated independently in each of the sites within their current ICT infrastructure; this is due to the local variations in systems.
- The number and complexity of components being implemented for the BeyondSilos project differs between sites; some regions have integrated a few components, such as electronic health and social records, to others which have also included triage systems, systems to help patient data management, decision support and scheduling, telecare communication, training platform, behaviour monitoring, vital sign monitoring, ambient monitoring, remote device administration, emergency communication, and personal data protection.
- Due to the differences and the complexity of the components being implemented and their technical characteristics, the training level of end users also varied across regions. However, a great focus has been given to training all end-users both at the start of the service and when needed through workshops, training from key staff members, and implementation of helpdesks.

4 Domain 2 and 3: Safety & clinical and care effectiveness

4.1 Introduction

Domains 2 & 3 concern the assessment of safety, and clinical and care effectiveness.

Safety is defined as the identification and assessment of harms related to the use of ICT supported integrated care services. In BeyondSilos, safety was divided into care related safety (mortality) and technical safety (issues related to the technical reliability of the service). Clinical and care effectiveness included assessments of type and numbers of contacts with care providers, as well as measurements of social support and clinical changes.

Two different approaches have been used to present the results:

- Site-level evaluations: In accordance with D6.1 Evaluation framework for BeyondSilos and D6.2 Interim evaluation report, the project evaluation is based on the deployment site evaluation reports. The full reports of the local evaluations are attached as annexes to this report. In this chapter, a short qualitative synthesis of the local evaluation reports is presented. Methodological considerations regarding this approach have been discussed in section 2.5.
- Project-level evaluation based on care recipient data (rather than on site evaluation data): In accordance with the revised evaluation plan introduced in the Year 2 Review Meeting, the project level evaluation is based on care recipient data rather than on site evaluation data, in order to take full advantage of having all the data in one common database. The results of this analysis are presented in sufficient detail. Due to the size of the analysis and the extent of results that have been produced, only the most important of them is presented in the main document, but additional results and analyses are available in the annexes.

4.2 Summary of deployment site-level evaluation reports

All sites have reported on the collected variables according to care group. Unadjusted results as well as results adjusted for relevant confounders, have been reported for all sites when possible, in accordance with the guidelines sent out to the sites.

4.2.1 Badalona

The overall interpretation of the statistical analyses within the Badalona site shows that the intervention developed within the BeyondSilos project service delivery has not shown significantly different results between the intervention and control groups regarding the clinical and care effectiveness. Even though unadjusted data showed some efficiency gains in terms of reduction of hospital admissions (either planned and unplanned), and in number of annual contacts, once confounders were taken into account, the analyses showed that the observed effects on the care groups are not statistically significant.

The interpretation of such findings in an isolated manner may initially suggest that the incorporation of the BeyondSilos service delivery has not improved the previous situation in terms of effectiveness. However, this must be viewed in a bigger picture. The BeyondSilos service was set up as an addition to the usual care services, not changing the planned contacts between formal caregiver and patient in order to ensure the safety of the patients before trusting the use of ICT completely.

The key performance indicators regarding technical safety were the main concern of the organisation. When analysing these, we can assure that there has been no problems compromising the safety of care recipients. The only problems encountered were before delivering the telemonitoring solution; these did not have an effect on the provision of services as intended.

4.2.2 Campania

The group of care recipients who received integrated care (IC) and the group of care recipients who received usual care (UC) had very similar baseline characteristics. All care recipients in both care groups had CHF as the main disease at enrolment.

Concerning the clinical characteristics based on measurements and laboratory exams, there were no significant differences between the two groups. Results regarding admissions to hospitals have not been collected for Campania, since all CRs in the project were receiving high level of intensive care as part of a home hospitalisation service. The care recipients in the IC group were followed for 303 days compared to 240 days in the UC group (p=0.042). Overall, care recipients most often had contact with nurses. Care recipients in the IC group had contacts with GPs and other healthcare providers less often, and more of them had contact with specialists and social workers compared to the UC group. The annual contacts rate was higher in the intervention group. The difference was not significant before adjustments for possible confounders, but the multiple linear regression model showed that ,after adjustments, the effect of care group is statistically significant and positive, indicating that the annual contacts rate has been increased significantly by 29.56 units in the intervention group, compared to the comparator group.

There were some technical issues related to the battery life which resulted in problems, as the caregiver and the care recipient were unable to operate the monitoring until the next visit from the nurse. This issue was overcome by procuring an extra set of batteries to be given to the caregiver or the care recipient to replace the exhausted ones.

4.2.3 Northern Ireland

Analysis indicates there is no difference in the number of hospital admissions between the care groups, although there is a clear trend against intervention group. After confounders were taken into consideration, the multiple negative binomial regression analyses showed that there was a statistically significant increase of length of hospitalisation in intervention group. Caution should be applied to this outcome because of the small number of patients for whom data was available. Of 51 patients with end data in the intervention group, only 11 had any hospital admissions; if 47 patients in the control group only four had any hospital admissions.

The number of contacts with health and social care professionals were significantly higher in the intervention group compared to the comparator group, considering no other confounders. Caution should be applied to this outcome because of the small number of patients for whom data was available. As patient selection and allocation to intervention or control group was made by the GPs, there is also the possibility of bias. GPs may have subconsciously selected patients for intervention from those with whom they, and/or their practice nurses, were already having more contacts which would have resulted in the higher numbers seen in the evaluation.

4.2.4 Sofia

The group of care recipients that received integrated care (IC) and the group of care recipients that received the usual care (UC) had very similar baseline characteristics. The most frequent primary and secondary diseases at enrolment were congestive heart failure (CHF) and diabetes for both care groups. However, care recipients from the IC group had CHF more often than care recipients from the usual care group. Concerning clinical characteristics based on measurements and laboratory exams, there were no significant differences between the two groups, with the exception of systolic blood pressure, pulse pressure and heart rate, which were higher in the intervention group.

Care recipients in the IC group was followed for 248 days compared to 246 days in the UC group (p=0.001). No difference in hospital admission or length of hospital stay was observed between the two care groups. Care recipients in the IC group had contacts with specialists and nurses less often, and more contacts with social workers compared to care recipients from the UC group. A slightly lower number of contacts per year has been seen in the intervention group. Multiple linear regression analysis, adjusting for gender, age, Charlson Comorbidity Index (CCI) at the enrolment, length of follow-up and primary disease has shown that BS integrated care services reduced annual contacts by 2.62 contacts, and that this reduction was significant.

4.2.5 Kinzigtal

Annual contacts with care professionals in the intervention group were less than in control group. This might be because of a better exchange of information between GPs and social care staff in the intervention group made some visits unnecessary. For example, information about vital parameters is now available in the electronic record, and does not need a home visit to examine these parameters. This could mean that BS service achieved the aim of reducing face-to-face contacts. However, it might also be a lack of documentation in the intervention group. We also found a decrease of social support in the intervention group. The number of CRs receiving social support was already smaller than in the control group at baseline; this might indicate a better health status on average in the intervention group overall, which is confirmed by a better health status regarding NYHA Classification, NIHSS, Charleston Comorbidity Index, diseases and comorbidities, which all indicated a more severe ill population in control group than in intervention group.

4.2.6 Valencia

The two care groups compared were very homogeneous. Participants in the Integrated Care group are more familiar with the use of PCs than participants in the Usual Care group. Some other differences were also observed between the groups in diastolic blood pressure (68.0 vs 69.3; P=0.013) and BMI (29.8 vs 28.9, p=0.008). A comparison analysis of the BeyondSilos service effects on clinical and anthropometric values showed no statistical differences between the groups. The adjusted analysis showed more hospital admissions in the Usual Care group, as was expected, but the differences are not significant. There is also a significantly high number of contacts in the Integrated Care group, also as expected, compared with the Usual Care group. No difference in mortality was observed between the two groups.

4.2.7 Amadora:

In Amadora, the median age of the population was 84 years old and 60% of participants were female. The most frequent primary and secondary diseases at enrolment were CHF, stroke and diabetes. All of the care recipients received logistic support and personal support, and less than 10% received technical or loan service support. The intervention period was significant longer than the historically comparison period (321 days for intervention vs 192 days for historical comparison).

4.2.8 Biases

Overall, most biases seems to have been introduced through measurement errors or missing values. A more detail discussion regarding this issue is provided in section 2.5. At site level, the following possible biases identified by the sites:

- Badalona reported that some of the information requested within the questionnaires was collected with help from professionals; we are aware that this could introduce an interpretation bias. We are also aware that some questionnaires were administered on paper and then transcribed into the online tool. This could also be a source of bias due to transcription errors.

- In Campania, the ADI is a programme that is used to provide high intensity (level 3) of care in the home. This implies that care recipients are home hospitalised. Indeed, hospitals activate ADI in order to discharge chronic patients from the hospital.
- Northern Ireland reported that as patient selection and allocation to intervention or control group was made by the GPs, there is the possibility of bias. The mix of rural and urban practices involved is a result of those practices which agreed to participate (i.e. chance) rather than as the result of any selection process. Whilst eight GP practices collected data at enrolment, only four provided any meaningful data at the end of the evaluation period.
- Sofia reported possible measurement errors in education and level of income which led to possible deviations from the local mean values.
- Valencia reported that some methods regarding delivery of questionnaire could lead to an interpretation bias.
- Amadora reported the following possible sources to bias. Given that the collection procedure was manual, the following potential constraints were taken in account:
  - Difficulties of the interviewers in understanding some questions.
  - Difficulties of the end users in understanding some questions.
  - Difficulties of the interviewers in understanding some answers provided by the end users.
  - Insufficient information provided by the end users.
  - Errors in the report of the answers provided by the end users
  - Errors transferring the information from the questionnaires to the CSV Files.
  - Lack of understanding of how to populate the CSV Files.

4.3 Project-level evaluation

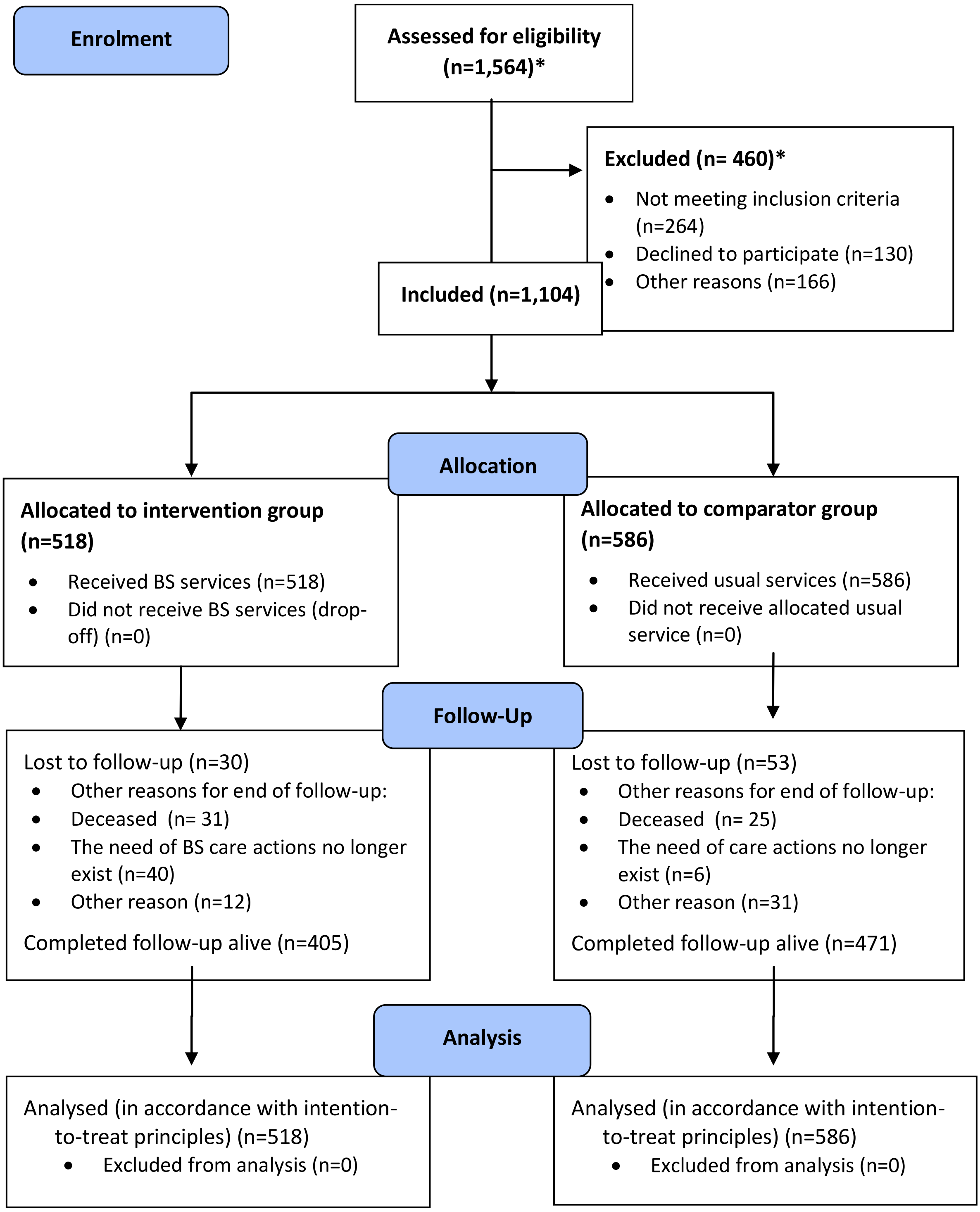
4.3.1 Results: Participants

The project evaluation cohort consisted of 1,104 care recipients (CRs); 518 in the intervention group (IG) received integrated care (IC), and 586 in the comparator group (CG) received usual care (UC) (Table 7). Most of the care recipients followed the long term pathway; only 40 CRs from Badalona were recruited to the short term pathway. All sites had parallel comparator groups except for Amadora, which used a historical comparator group.

Table 7: The project population per group and per deployment site

	IG	CG	Total	NIR	BAD	VAL	CAM	AMA	KIN	SOF
N (all in database)	519	587	1106	168	199	165	100	141	91	100
Excluded	1	1	2	0	1	0	0	1	0	0
Evaluation cohort	518	586	1104	168	198	165	100	141	91	100
Long term pathway	497	566	1063	168	158	165	100	141	91	99
Short term pathway	21	20	41	0	40	0	0	0	0	1
Parallel comparator group	123	446	569	94	157	165	50	0	53	50
Historical comparator group	0	141	141	0	0	0	0	141	0	0

Abbreviations: IG- Intervention group, CG- Comparator Group, NIR – Northern Ireland, BAD – Badalona, VAL – Valencia, CAM – Campania, AMA – Amadora, KIN – Kinzigtal, SOF - Sofia



*Information based on reporting's from pilot sites and not from the Central web database.

Figure 8: Flowchart describing the flow of care recipients

An overview of care recipients' flow is presented in Figure 8. Numbers from the pilot sites indicate that 1,564 care recipients were assessed for eligibility between the pilot sites, 1,104 were invited to participate in the BeyondSilos (BS) project, and 460 were excluded. Reasons for exclusion were: Did not meet the inclusion criteria (264), declined to participate (130), and exclusion for other reasons (166) (e.g. having a high probability of being lost to follow-up, declining to participate after new BeyondSilos care had been explained to them, or belonging to a geographic area not including the BS service). Almost 80% of the population completed the full follow-up period alive. Most common reason for drop outs once included in the BS project were: No need for further BS service, deceased, or lost to follow-up (Figure 8).

4.3.2 Results: Baseline characteristics

The baseline demographic characteristics of the population under evaluation are presented in the Table 8.

The group of care recipients that received integrated care (IC), and the group of care recipients that received the usual care (UC), had very similar baseline characteristics. More than half of the CRs were female, and more than 80% were more than 75 years old. Kinzigtal had the highest percentage of women included in their study population (70%), while Valencia included the least women (44%). Sofia had the youngest population with a median age of 76 years, while Kinzigtal had the oldest population with a median age of 84 years. Care recipients in both care groups were characterised by being either married or widowed, having less than primary school education, being home owners (compared to renters), being non-smokers, and not drinking alcohol over the last 12 months. The care recipients from Northern Ireland had attended school the longest (71% with secondary school education or more), while CRs from Amadora and Valencia had attended school the shorted (12% with secondary school education or more). Both groups were more familiar with using mobile phones (more than 55%) and less with using computer (between 15% and 18%).

Around 60% of the care recipients had received some kind of social support (most often logistic support such as "meals", "cleaning") at the beginning of the BeyondSilos project (Table 9). It seems that CRs from the intervention group more often received “technical support” such as panic button, GPS tracking (49% vs 23%) and had “personal support” such as family workers or day care centres (60% vs 52%), than CRs from the comparator group.

Concerning clinical characteristics based on measurements and laboratory exams, there were no significant differences between the two groups, with the exception of diastolic blood pressure and heart rate which were higher in the intervention group, and oxygen saturation which was worse in the same group (Table 10).

Table 8: Demographic characteristics of population under evaluation

	Intervention group		Comparator group		P-value	Total	
	N or Median	% or IQR	N or Median	% or IQR		N or Median	% or IQR
Female (N, %)	308	59.5%	333	56.8%	0.376	641	58.1%
Age (years)	82.30	7.54	81.42	7.83	0.076	81.83	7.70
Age group (N, %)							
<65	2	0.4%	7	1.2%	0.188	9	0.8%
65-75	96	18.7%	124	21.2%		220	20.0%
>75	415	80.9%	455	77.6%		870	79.2%
Marital status (N, %)							
Never married	28	6.1%	40	7.6%	0.491	68	6.9%
Currently married	179	38.8%	229	43.3%		408	41.2%
Separated	7	1.5%	10	1.9%		17	1.7%
Divorced	20	4.3%	22	4.2%		42	4.2%
Widowed	225	48.8%	225	42.5%		450	45.5%
Cohabitating	2	0.4%	3	0.6%		5	0.5%
Level of education (N, %) (education)							
Less than primary school	178	41.9%	207	40.5%	0.088	385	41.1%
Primary school	111	26.1%	159	31.1%		270	28.8%
Secondary school	56	13.2%	70	13.7%		126	13.5%
High school	26	6.1%	29	5.7%		55	5.9%
College/University	29	6.8%	34	6.7%		63	6.7%
Post graduate degree	25	5.9%	12	2.3%		37	4.0%

	Intervention group		Comparator group		P-value	Total	
	N or Median	% or IQR	N or Median	% or IQR		N or Median	% or IQR
Longest held occupation (N, %) (occupation)							
Manual	109	27.5%	217	43.5%	0.000	326	36.4%
Non manual	91	22.9%	87	17.4%		178	19.9%
Unemployed (able to work)	0	0.0%	1	0.2%		1	0.1%
Unemployed (unable to work)	143	36.0%	142	28.5%		285	31.8%
Homemaker	54	13.6%	52	10.4%		106	11.8%
Household income (yearly in euro) (income)							
0-6.999	141	48.3%	160	42.8%	0.479	301	45.2%
7.000-13.999	117	40.1%	172	46.0%		289	43.4%
14.000-19.999	27	9.2%	34	9.1%		61	9.2%
20.000 or more	7	2.4%	8	2.1%		15	2.3%
Housing tenure (tenure)							
Owners	346	80.7%	372	78.5%	0.419	718	79.5%
Renters	83	19.3%	102	21.5%		185	20.5%
Number of people older than 18 living in household in addition to the patient (Median, IQR)	1.00	(0.00-2.00)	1.00	(0.00-2.00)	0.833	1.00	(0.00-2.00)
Familiar with using mobile (N, %)	295	59.1%	328	57.3%	0.557	623	58.2%
Familiar with using computer (N, %)	90	18.1%	84	15.1%	0.186	174	16.5%
Tobacco use (tobacco)							
Never	327	66.7%	354	62.8%	0.217	681	64.6%
Former	139	28.4%	164	29.1%		303	28.7%
Current smoker	20	4.1%	42	7.4%		62	5.9%
e-cigarette	1	0.2%	1	0.2%		2	0.2%
Other	3	0.6%	3	0.5%		6	0.6%
Frequency of alcohol drinking past 12 months (alcohol)							
None	398	81.7%	399	73.9%	0.018	797	77.6%
Less than 1/week	63	12.9%	91	16.9%		154	15.0%
1-7/week	24	4.9%	47	8.7%		71	6.9%
8-14/week	2	0.4%	3	0.6%		5	0.5%
>14/week	0	0.0%	0	0.0%		0	0.0%

Abbreviations: IQR = interquartile range (the midspread or middle 50%)

Table 9: Social support before enrolment

	Intervention group		Comparator group		P-value	Total	
	N	%	N	%		N	%
SOCIAL SUPPORT							
Technical support such as "panic button", "GPS tracking" as a new service during the evaluation period	186	45.8%	107	22.7%	0.000	293	33.4%
Logistic support such as "meals", "cleaning", "laundry", "home fixing" as a new service during the evaluation period	254	62.6%	270	57.2%	0.107	524	59.7%
Personal support such as "family workers", "day care centres", "punctual accompaniment (to medical visits)", "company for risk exclusion avoidance" as a new service during the evaluation period	244	60.1%	243	51.5%	0.010	487	55.5%
Loan services support such as "wheel chairs", "crutches", "adapted bed" as a new service during the evaluation period	143	35.2%	170	36.0%	0.806	313	35.6%

Table 10: Anthropometric, clinical and laboratory exams

	Intervention group		Comparator group		P-value	Total	
	Mean or N	SD or %	Mean or N	SD or %		Mean or N	SD or %
Weight (kgs)	71.54	15.90	70.99	14.87	0.786	71.25	15.37
Height (cm)	161.95	9.39	162.51	9.30	0.398	162.25	9.34
Body Mass Index (kg/m^2)	27.20	5.45	26.82	5.11	0.331	27.00	5.28
Systolic blood pressure (mmHg)	128.80	17.51	131.63	18.87	0.089	130.23	18.26
Diastolic blood pressure (mmHg)	74.69	12.00	72.38	11.14	0.037	73.52	11.62
Pulse pressure (mmHg)	56.23	15.50	59.42	17.99	0.057	57.87	16.89
Mean Arterial Pressure (mmHg)	92.72	11.00	92.12	11.22	0.557	92.42	11.11
Heart rate (bpm)	75.59	13.38	74.07	12.08	0.049	74.84	12.78
Oxygen saturation (%)	92.80	7.44	95.06	3.46	0.038	93.86	6.02
Blood glucose (mg/dl)	127.66	60.53	119.46	45.41	0.786	124.28	54.85
HbA1c (%)	7.07	1.73	7.04	1.61	0.960	7.05	1.67
Creatinine (mg/dl)	1.21	0.74	1.12	0.50	0.625	1.17	0.64
eGFR (mg/dl/1.73m^2))	69.88	37.77	73.66	41.46	0.543	71.67	39.53

4.3.3 Primary diseases and comorbidities

The most frequent primary and secondary diseases at enrolment were congestive heart failure (CHF) and diabetes for both care groups (Table 11). Less than 25% of the enrolled CRs had another disease as primary disease for enrolment, which reflect mainly the care recipients from Badalonaand Valencia.

Table 11: Primary and secondary diseases

	Intervention group		Comparator group		P-value	Total	
	N	%	N	%		N	%
Primary disease at enrolment							
CHF	190	56.4%	249	63.5%	0.050	439	60.2%
Stroke	25	7.4%	28	7.1%	0.895	53	7.3%
COPD	46	13.6%	59	15.1%	0.569	105	14.4%
Diabetes	72	21.2%	65	16.6%	0.108	137	18.7%
Fracture	9	2.7%	10	2.6%	0.934	19	2.6%
Secondary disease at enrolment							
CHF	52	15.3%	32	8.2%	0.002	84	11.5%
Stroke	15	4.4%	11	2.8%	0.239	26	3.6%
COPD	37	10.9%	37	9.4%	0.509	74	10.1%
Diabetes	63	18.6%	99	25.3%	0.030	162	22.2%
Fracture	13	3.8%	2	.5%	0.002	15	2.1%

The Charlson Comorbidity Index (CCI) and the Age-Adjusted CCI (AACCI) was used to assess the comorbidities of CRs in the BS project. No significantly difference in the CCI or the AACCI was observed between the two care groups, indicating that the severity and complexity of the comorbidities were similar in the two care groups. A question regarding presence of HIV infection was not included in the assessment due to regional bioethical regulations, which state that it is not allowed to ask for the presence of HIV infection. However, it was agreed that excluding this question was not expected to affect the final assessment significantly, as it was assumed that the prevalence of HIV infection in the evaluation cohort would be low.

Table 12: Assessment of comorbidities

	Intervention group		Comparator group		P-value	Total	
	N	%	N	%		N	%
Assessment of Comorbidity							
Charlson Comorbidity Index at enrolment (mean, SD)	4.26	2.65	4.45	2.45	0.080	4.36	2.55
Age Adjusted Charlson Comorbidity Index at enrolment	8.05	2.78	8.31	2.45	0.055	8.19	2.61
Total number of comorbidities at enrolment (median, IQR)	2.00	(1.00-4.00)	3.00	(2.00-4.00)	0.127	2.00	(2.00-4.00)
Comorbidities							
Myocardial infarction	54	16.0%	64	16.9%	0.756	118	16.5%
Congestive heart failure	154	46.2%	186	49.3%	0.411	340	47.9%
Peripheral vascular disease	6	1.9%	7	1.9%	0.961	13	1.9%
Cerebrovascular disease	101	30.5%	103	27.6%	0.397	204	29.0%
Dementia	28	8.4%	40	12.2%	0.109	68	10.3%
Chronic pulmonary disease	15	4.8%	30	8.2%	0.077	45	6.7%
Rheumatic disease	37	11.0%	50	13.2%	0.388	87	12.2%
Peptic ulcer disease	78	23.4%	80	21.1%	0.458	158	22.2%
Mild liver disease	71	21.5%	89	24.0%	0.436	160	22.8%
Diabetes without chronic complication	115	35.1%	147	38.7%	0.319	262	37.0%
Diabetes with chronic complication	81	23.9%	72	18.9%	0.102	153	21.3%
Hemiplegia or paraplegia	98	29.3%	109	28.8%	0.882	207	29.1%
Renal disease	5	1.6%	10	2.7%	0.291	15	2.2%
Any malignancy, including lymphoma and leukaemia, except malignant neoplasm of skin	40	12.5%	24	6.6%	0.008	64	9.4%
Moderate or severe liver disease	14	4.3%	16	4.3%	0.984	30	4.3%
Metastatic solid tumour	58	17.3%	70	18.2%	0.761	128	17.8%

4.3.4 Results: Follow-up of care recipients

Overall, about 80% of CRs in the BeyondSilos project completed the follow-up period as planned. More CRs were lost to follow-up in the IC group than in the UC group. However, the IC group were also followed for a longer period than the UC group (IC 244.8±104.29 day's vs UC 205.92±67.78 days). When assessing only CRs with a length of follow-up of 90 days or more (used for the logistic analyses), the follow-up period for the IC group increased to 265.57±85.89 days and to 219.35 days for the UC group.

Concerning clinical characteristics based on measurements and laboratory exams (Table 13), there were no significant differences in changes of values between the two groups, with the exception of diastolic blood pressure which seems to have dropped significantly more in the IC group compared to the UC group, and the blood glucose level which also had dropped significantly more in the IC group compared to the UC group, which might indicate a better monitoring of diabetes patients in the IC group. Results of data on New York Heart Association (NYHA) Functional Classification of patients with chronic heart failure at enrolment and at the end of follow-up, The National Institutes of Health Stroke Scale (NIHSS) of patients with stroke at enrolment and at the end of follow-up, as well as Social support at the end of follow-up, can be viewed in Appendix A.

Table 13: Mean length and reasons for end of follow-up

	IC group		UC group		P-value	Total	
	Mean (or N)	SD (or %)	Mean (or N)	SD (or %)		Mean (or N)	SD (or %)
Length of follow-up (days)	244.8	104.29	205.92	67.78	0.000	224.34	89.10
Length of follow-up (>=90days)	265.57	85.89	219.35	51.19	0.000	241.03	73.34
Reasons for end of follow-up (N, %)							
Care recipients completed follow-up	405	78.0%	471	80.2%	0.000	876	79.2%
Deceased	31	6.0%	25	4.3%		56	5.1%
No longer need of BS services	40	7.7%	6	1.0%		46	4.2%
Other reason	12	2.3%	31	5.3%		43	3.9%
Missing	30	6.0%	53	9.2%		85	7.7%

Table 14: Impact on anthropemetirc, clinical and lab exams

Measurement	Intervention Group	Comparator Group	Unadjusted BeyondSilos effect	Adjusted BeyondSilos effect
Body weight (N=771 -> 722)				
Enrolment	70.79 (16.43)	70.49 (14.38)		
End	71.87 (16.84)	70.55 (14.54)		
Change	1.08 (-0.02, 2.18)	0.05 (-0.31, 0.2)	0.54 (0, 2.26)	-0.042 (-0.485, 0.402)
p value	0.154	0.854	0.717	0.485
BMI (N=760 -> 716)				
Enrolment	26.81 (5.52)	26.6 (4.91)		
End	27.18 (5.69)	26.58 (4.88)		
Change	0.37 (-0.03, 0.76)	-0.02 (-0.12, 0.09)	0.17 (-0.02, 0.79)	0.028 (-0.153, 0.209)
p value	0.067	0.989	0.427	0.762
Systolic blood pressure (N=473 -> 463)				
Enrolment	127.72 (18.2)	132.85 (17.8)		
End	127.69 (17.78)	130.51 (16.74)		
Change	-0.03 (-2.7, 2.65)	-2.33 (-4.03, -0.64)	-1.29 (-0.86, 5.47)	2.579 (-0.11, 5.268)
p value	0.880	0.027	0.852	0.120
Diastolic blood pressure (N=468 -> 452)				
Enrolment	76.62 (12.95)	74.69 (10.74)		
End	75.91 (11.81)	74.48 (10.6)		
Change	-0.72 (-2.29, 0.86)	-0.21 (-1.19, 0.76)	-0.44 (-2.35, 1.34)	-1.527 (-3.059, -0.016)
p value	0.318	0.484	0.861	0.048
Pulse Pressure (N=450 -> 441)				
Enrolment	54.08 (15.56)	58.45 (18.22)		
End	53.28 (16.32)	56.45 (16.94)		
Change	-0.8 (-3.12, 1.52)	-2 (-3.67, -0.34)	-1.48 (-1.65, 4.05)	-0.09 (-2.497, 2.318)
p value	0.116	0.027	0.517	0.942
Mean arterial pressure (N=450 -> 444)				
Enrolment	93.37 (12.02)	94.09 (10.21)		
End	93.18 (10.97)	93.21 (9.89)		
Change	-0.19 (-1.63, 1.26)	-0.88 (-1.88, 0.11)	-0.58 (-1.05, 2.44)	0.677 (-0.9, 2.255)
p value	0.880	0.134	0.632	0.399

Measurement	Intervention Group	Comparator Group	Unadjusted BeyondSilos effect	Adjusted BeyondSilos effect
Heart rate (N=420 -> 405)				
Enrolment	74.95 (12.3)	72.7 (11.82)		
End	74.34 (12.61)	72.95 (11.95)		
Change	-0.61 (-2.73, 1.5)	0.25 (-0.87, 1.37)	-0.15 (-3.16, 1.43)	-0.69 (-2.544, 1.163)
p value	0.513	0.785	0.874	0.465
Oxygen saturation (N=235 -> 229)				
Enrolment	90.56 (8.43)	93.14 (3.2)		
End	90.46 (7.5)	93.02 (3.21)		
Change	-0.1 (-1.43, 1.23)	-0.12 (-0.53, 0.28)	-0.11 (-1.37, 1.41)	-0.052 (-0.833, 0.729)
p value	*0.860*	*0.080*	*0.733*	*0.895*
Blood glucose (N=109 -> 103)				
Enrolment	144.39 (73.77)	123.48 (55.52)		
End	127.25 (54.95)	127.42 (60.22)		
Change	-17.15 (-37.9, 3.6)	3.94 (-4.03, 11.91)	-7.86 (-43.2, 1.03)	-19.505 (-34.957, -4.052)
p value	*0.066*	*0.515*	*0.080*	*0.014*
HbA1c (N=50 -> 44)				
Enrolment	6.73 (1.15)	6.93 (1.37)		
End	7 (1.37)	6.94 (1.36)		
Change	0.27 (-0.1, 0.64)	0.01 (-0.05, 0.07)	0.12 (-0.34, 0.68)	0.119 (0.062, 0.176)
p value	*0.075*	*0.998*	*0.046*	*0.000*
Creatinine (N=116 -> 107)				
Enrolment	1.29 (0.92)	1.08 (0.52)		
End	1.34 (0.97)	1.12 (0.53)		
Change	0.05 (-0.16, 0.27)	0.05 (-0.01, 0.1)	0.05 (-0.17, 0.19)	0.034 (-0.005, 0.072)
p value	*0.071*	*0.394*	*0.103*	*0.085*
eGFR (N=116 -> 103)				
Enrolment	72.69 (52.02)	78.82 (44.61)		
End	66.85 (43.35)	75.91 (42.78)		
Change	-5.84 (-16.54, 4.86)	-2.91 (-12.36, 6.51)	-4.00 (-27.38, 12.10)	-1.68 (-3.745, 0.385)
p value	*0.131*	*0.414*	*0.123*	*0.110*

Quantitative data presented as mean (SD), unless otherwise indicated. The adjusted effect is calculating adjusting for age, gender, region, length of follow-up and Charlson Comorbidity Index.
* Statistically significant p-value (p<0.05) ** Statistically significant p-value (p<0.01)

4.3.5 Result: Impact on hospital admissions

In Table 15, the data concerning hospital admissions, including total planned and unplanned hospital admissions, are presented without any adjustments. The adjusted results are presented in Table 16.

Overall, 40% of CRs in the intervention group and 46% in the comparator group were hospitalised during the follow-op period. The unadjusted analyses showed that although the first admission to hospital occurred earlier for the IC group (IC 80.44 days vs UC 87.11 days, p = 0.018), their annual admission rate (IC 1.29 vs 2.08, p= 0.004) and annual length of hospital stay (IC 4.03 vs UC 4.10) were significantly lower than for the UC group. Furthermore, the IC group had a significantly lower readmission rate to hospital within 30 days (IC 0.47 vs UC 1.73, p = 0.000), and had fewer unplanned hospital admissions (IC 40.3% vs UC 54.2%, p = 0.000), even though they had a longer follow-up period.

Care recipients from both care groups were more often admitted to both Geriatric and Internal Medicine Departments (more than 60%) than to the Cardiology Department (around 14%). However, a significantly higher percentage of the IC group admissions were to the Accident & Emergency department (IC 12.7% vs

UC 2.3%, p<0.001). Care recipients were most often discharged to their home (around 90%), and only few in-hospital deaths were reported in both groups (1%).

Table 15: Hospital admissions per care group

	Integrated care group		Usual care group		P-value	Total	
	Mean or N	SD or %	Mean or N	SD or %		Mean or N	SD or %
Unadjusted data							
Number of hospitalisations	386		515			901	
Total numbers of days in hospital	1148		1129			2277	
Mean length of hospital stay per admission	3.25	6.14	2.57	3.42	0.675	2.87	4.83
Mean Length of hospital stay per patient (in days)	5.89	9.81	4.65	6.11	0.459	5.20	7.98
Days till first admission	80.44	74.64	87.11	62.42	0.018	84.14	68.14
Mean number of admissions per patient (all patients)	0.88	1.22	1.06	1.48	0.106	0.98	1.37
Mean number of admissions per patient (among hospitalized)	1.98	1.09	2.12	1.46	0.689	2.06	1.31
Patients with readmissions	136	27.9%	146	27.4%	0.865	282	27.6%
Number of readmissions within 30 days (readmission)	64		253			317	
Mean number of readmissions within 30 days per patient	0.47	1.05	1.73	1.44	0.000	1.12	1.42
Number of hospitalisations by type							
Planned	230	59.7%	236	45.8%	0.000	466	51.8%
Unplanned	155	40.3%	279	54.2%		434	48.2%
Hospital department where the patient was admitted (N, %)							
Geriatric and internal medicine	232	60.1%	360	69.9%	0.002	592	65.7%
Cardiology	54	14.0%	76	14.8%	0.746	130	14.4%
Accident and emergency (A&E)	49	12.7%	14	2.7%	0.000	63	7.0%
Critical care and intensive care	5	1.3%	1	0.2%	na	6	0.7%
Surgical department	9	2.3%	10	1.9%	0.687	19	2.1%
Home hospitalization	8	2.1%	0	0.0%	na	8	0.9%
Orthopedics	6	1.6%	3	0.6%	na	9	1.0%
Neurosurgery	17	4.4%	29	5.6%	0.408	46	5.1%
Other	6	1.6%	22	4.3%	0.021	28	3.1%
Discharge destination (N, %)							
Home	340	88.1%	464	90.1%	0.335	804	89.2%
Nursing home	4	1.0%	1	0.2%	na	5	0.6%
Death	4	1.0%	5	1.0%	0.992	9	1.0%
Other	37	9.6%	44	8.5%	0.589	81	9.0%
Missing answer	1	0.3%	1	0.2%	na	2	0.2%
Annual rates for admissions							
Length of follow-up	265.57	85.89	219.35	51.19	0.000	241.03	73.34
All admissions							
Annual admissions rate	1.29	1.86	2.08	2.86	0.004	1.72	2.48
Annual length of hospital stay	4.03	11.67	4.10	8.02	0.012	4.07	9.85
Only Unplanned Admissions							
Annual number of unplanned admissions	0.61	1.50	1.08	1.92	0.000	0.87	1.75
Annual Length of hospital stay for unplanned admissions	2.32	8.79	2.40	6.52	0.000	2.37	7.64

Table 16 shows the associations between type of care group (IC vs UC) and number of hospital admissions, total number of days in hospital, number of unplanned hospital admissions, and total number of days of unplanned hospital admissions. Only CRs with a length of follow-up longer than 90 days were included in the analysis; which is about 90% the population. Results regarding admissions to hospitals have not been collected for Campania, since all CRs were receiving high level of intensive care as part of a home hospitalisation service. In Sofia, there were numbers of events to be included in the regression analyses, and in Kinzigtal, information regarding hospital admissions has only been collected for the UC group due to problems in the data collection from the subcontracted the care provider. Therefore Campania, Sofia and the IC group of Kinzigtal are not included in the project level analyses.

The unadjusted analyses show that even though the total number of admissions to hospital was lower for the IC group than for the UC group, by 15% (IRR of the number of hospital admission for the comparator group is 1.15 times the IRR for the IC), the total number of days in hospital was higher for the IC group compared to the UC group by 3% (IRR of the total number of days in hospital for the comparator group is 0.97 times the IRR for the IC). However, both results were not statistically significant. After adjusting for gender, age, Charlson Comorbidity Index (CCI) at enrolment, length of follow-up (>=90days included), primary disease and region, the associations were further weakened, and remained not statistically significant; thus no significant difference in the number of hospital admissions and number of days in hospital were found between the care groups. Negative binomial regression analysis of hospital admissions and days in hospital confirmed these findings. The analyses showed no difference between care groups, but that other confounders were more important at predicting hospitalisations and length of hospital stay, such as the presence of congestive heart failure or region, and for hospital length, also a shorter length of follow-up. Concerning the impact of site-specific characteristics, it seems that care recipients from Badalona, Amadora and Valencia were more likely to have a hospital admission and a longer hospital stay than their comparators outside their region, and that CRs from Kinzigtal were less likely to stay for a longer period in the hospital than the comparators outside their region, when taking the above mentioned confounders into consideration. The negative binomial regression analyses can be viewed in full in Appendix B.1 & B.2.

A significantly lower number of unplanned hospital admissions were observed for the IC group by 53% (IRR=1.53, 95%CI: 1.19-1.95). However, after adjustment for a number of possible confounders, this difference was no longer found to be statistically significant. Negative binomial regression analysis of number of unplanned hospital admissions confirmed these results, and showed that presence of congestive heart failure, region of origin, and a shorter length of follow-up were more important when describing the difference in unplanned hospitalisations. Concerning the impact of site-specific characteristics, it seemed that care recipients from Badalona, Amadora and Valencia were more likely to have an unplanned hospital admission than their comparators outside their region. The negative binomial regression analyses can be viewed in full in Appendix B.3.

Finally, the analysis showed that the total number of days of unplanned hospital admissions was non-significantly lower in the IC group than in the UC group. This trend was further weakened after adjusting for confounders (no statistically significant difference). Negative binomial regression analysis of total number of days of unplanned hospital admissions confirmed the results, and showed that being a woman, the presence of congestive heart failure, region, and a shorter length of follow-up were more important when describing the difference in number of days of unplanned hospital admissions. Concerning the impact of site-specific characteristics, it seems that CRs from Amadora and Valencia were more likely to have a longer unplanned hospital stay than their comparators outside their region, and that CRs from Kinzigtal and Northern Ireland were less likely to stay for a longer period during an unplanned hospital stay than the comparators outside their region. The negative binomial regression analyses can be viewed in full in Appendix B.4.

Table 16: Adjusted and unadjusted impact on hospital admissions per care group

	Unadjusted	Confounder adjusted**
	Effect size (95% CI)	Effect size (95% CI)
1) Total number of admissions to hospital		
Control	IRR[1] =1.15, (95%CI: .95-1.40), p =.159 [b]	IRR [1]=1.02, (95%CI: .77-1.34), p =.894 [b]
Intervention	reference	reference
2) Total number of days in hospital		
Control	IRR[1]=.97, (95%CI: .83-1.15), p =.741 [b]	IRR[1]=.90, (95%CI: .72-1.11), p =.315 [b]
Intervention	reference	reference
3) Total number of unplanned admissions		
Control	IRR[1]=1.53, (95%CI: 1.19-1.95), p < .001 *[b]	IRR[1]=1.10, (95%CI: .81-1.49), p =.543 [b]
Intervention	reference	reference
4) Total number of days of unplanned admissions in hospital		
Control	IRR[1]=1.07, (95%CI: .89-1.28), p =.465 [b]	IRR[1]=1.04, (95%CI: .79-1.37), p =.776 [b]
Intervention	reference	reference

[b] Negative binomial regression; * Statistically significant result

** Adjusted for care group, gender, age, Charlson Comorbidity Index (CCI) at the enrolment, Length of Follow-up (>=90days included), primary disease and region

[1] IRR= incident rate ratio= Exp(B)

4.3.6 Result: Impact on contacts with health and social care professionals

In total, more than 37,800 contacts with health and social care professionals were recorded, 13,507 for the IC group and 24,322 for the usual care group (Table 17). In one site, Amadora, the total number of contacts registered were so large (81,593 contacts) that the statistical team asked for additional validation and clarification of these data. The site described that part of the design of the service was that CRs might have six visits per day from staff, even to deliver drug treatment. However, in the end it was decided to exclude Amadora from the analyses due to severe outliers and some inconsistency in data collection.

The overall annual contact rate (IC 63.25 vs UC 95.43, p<0.000) and the annual physical contact rate (IC 9.48 vs UC 11.94, p=0.015) was found to be significantly lower for the IC group than for UC group. Of the registered contacts, 14% were unplanned contacts with a care professional. The IC group seemed to have a higher annual rate of unplanned contacts than UC group; however, this difference was not found statistically significant (IC 2.57 vs UC 1.93, p=0.055). When examining the contacts divided by care profession, it showed that recipients from both groups most often had contact with nurses (72.4%), but that the contact rate with nurses was significantly higher for the UC group than for the IC group. The IC groups more often had contact with GPs, social workers, specialists, rehabilitation therapists, and other healthcare providers compared to the UC group. The fact that the new integrated service was often led by either GPs (e.g. Northern Ireland) or social care institutions (e.g. Kinzigtal, Amadora and Sofia) might explain the higher number of contacts with GPs and social workers among the IC group. Contacts were more often conducted by telephone (IC 49.4% vs UC 20.2%, p<0.000) or by home visits (IC 30.7% vs UC

25.9%, p<0.000) for the IC group, and less often by physical meetings outside of the home residence, such as a doctor's office or rehabilitations centre (IC 6.7% vs UC 21.2%, p<0.000) compared to the UC group.

Table 17: Impact on contacts with health and social care professionals per care group*

	Intervention group		Comparator group		P-value	Total	
	N	%	N	%		N	%
Total number of contacts (sum)	**13507**	**35,7%**	**24322**	**64,3%**		**37829**	
GPs	1595	11.8%	1840	7.6%	0.000	3435	9.1%
Specialists	914	6.8%	910	3.7%	0.000	1824	4.8%
Nurses	8560	63.4%	18822	77.4%	0.000	27382	72.4%
Rehabilitation therapists	155	1.1%	372	1.5%	0.002	527	1.4%
Other health care provider	832	6.2%	914	3.8%	0.000	1746	4.6%
Social workers	1451	10.7%	1459	6.0%	0.000	2910	7.7%
Volunteers	0	0.0%	5	0.0%	na	5	0.0%
Number of contacts per type							
Planned	2389	85.6%	1359	87.6%	0.071	3748	86.3%
Unplanned	402	14.4%	193	12.4%		595	13.7%
Contact type (N, %)							
Physical meeting out of home	239	6.7%	563	21.2%	0.000	802	12.9%
Home visit	1089	30.7%	687	25.9%	0.000	1776	28.7%
Telephone	1751	49.4%	535	20.2%	0.000	2286	36.9%
Writing (e-mail, SMS, etc.)	463	13.0%	857	32.3%	0.000	1320	21.3%
Other	6	0.2%	8	0.3%	0.276	14	0.2%
Annual rates for contacts							
Length of follow-up	265.57	85.89	219.35	51.19	0.000	241.03	73.34
Annual contacts rate	63.25	81.45	95.43	206.83	0.000	80.714	162.70
Annual unplanned contacts rate	2.57	5.07	1.93	4.25	0.055	2.303	4.75
Annual physical contacts rate	9.48	18.83	11.94	17.42	0.015	10.498	18.28

* The pilot site of Amadora has been excluded from the analyses due to severe outliers and inconsistency in data collection. For local analyses of Amadora please see annex.

Multiple linear regression analyses of the association between type of intervention and annual contact rates were performed. Due to technical problems related with data collection and uploading, Amadora had to be excluded from the analyses of annual contacts. The initial bivariate analysis suggested that receiving integrated care was associated with fewer annual contacts with health and social care professionals. More specifically, the analysis showed that there were significantly fewer annual contacts, by on average 32.17 contacts, in the IC group compared with the UC group. However, when adjusting for the confounders (gender, age, Charlson Comorbidity Index (CCI) at enrolment, length of follow-up (>=90days included), primary disease and region), this association was reversed and the analysis suggested that receiving integrated care was associated with on average 16.15 more contacts per year compared to receiving usual care. The analysis showed that the confounders region, length of follow up (LFU), Charlson Comorbidity Index (CCI) at enrolment, primary congestive heart failure had a statistically significant effect on the annual contact rate.

When examining the annual contacts rate at a site level, large significant diversity in the results was found. In Northern Ireland, Sofia and Kinzigtal, CRs from IC group had significant fewer contacts compared to UC group, whereas in Campania and Valencia CRs from IC group had a significant more contacts compared to UC group. Only Badalona did not observe a significant difference in annual contacts between the two care groups. The lower number of contacts in the IC group in Kinzigtal could have been caused due to under reporting of contacts by the social care organisation responsible for the data collection in the IC group, since they were a different organisation than for the UC group, and some variation in data quality was observed. In Valencia, an underreporting of contacts for the UC group was reported due to technical problems related to data uploading.

Table 18: Multiple linear regression analysis for the impact on contacts with health and social care professionals

	Unadjusted	Confounder adjusted**
Annual contacts rate	Effect size (95% CI)	Effect size (95% CI)
Intervention	b^2=-32.17, (95%CI: -57.62-6.72), $p < 0.05$ *[a]	b^2=16.15 (95%CI: 9.830-22.48), $p < .001$ *[a]
Control	reference	reference

a Multiple linear regression; * Statistically significant result

** Adjusted for care group, gender, age, Charlson Comorbidity Index (CCI) at enrolment, length of follow-up (>=90days included), primary disease and region

[2] b = Unstandardised Coefficient B (If the regression beta coefficient is positive, the interpretation is that for every 1-unit increase in the predictor variable, the dependent variable will increase by the unstandardised beta coefficient value.)

4.3.7 Results: Safety

4.3.7.1 Care related safety:

The main clinical indicator for safety was mortality. No significant difference in the mortality rates between the care groups was observed. For the IC group, the mortality rate was 6.0%, and 4.2% for the UC group (Table 19). The mean age of the deceased care recipients was more than 83 years old (IC 83.4 vs UC 84.4 years old).

Table 19: Mortality

Variable/measurement	All N	Integrated care N	Usual care N	Difference (p)
Mortality				
Deaths, N (%)	56	31 (6.0%)	25 (4.2%)	0.194

4.3.7.2 Technical related safety

The sites were asked to report on issues related to the technical reliability of the service that could cause harm to any of the users. However, no technical safety implications were reported, only technical problems which were resolved. BeyondSilos services seem safe from a technical point of view.

The following technical issues were highlighted by the sites:

- **Campania**: Some technical issues related to battery life resulted in problems, as the caregiver and the care recipient were unable to operate the monitoring until the next visit from the nurse. This issue was overcome by procuring an extra set of batteries to be given to the caregiver or the care recipient to replace the exhausted ones.
- **Badalona**: There were just five users in the intervention group that had problems with the connection of the tablet / PCs. This happened because the living rooms (the place where we usually installed the platforms) were in the inner part of the buildings, and the 4G connection did not reach properly. We were able to move the tablet / PCs to the bedrooms that were in the outside part, and everything was fine. There were no adverse events to highlight within the intervention time for the Badalona site.

- **Sofia**: Connection problems meant that the telemonitoring devices did not transmit data to the database in 25 cases. Fixed-line internet was provided besides the 3G mobile internet. In 30 cases, the batteries of the devices ran out quickly, so chargers were provided.
- **Valencia**: Most issues regarding technology were minor problems. We documented 54 issues regarding connections, system log in and log out, loading data and communications which had easy solutions, such as re-starting system or devices, or changing minor parameters. Case management nurses reported some problems loading some patients' data; TSB provided an updated version. We detected six minor failures regarding peripheral devices due to some failures in Bluetooth connection; care recipients could enter data manually and re-start system to solve problems. At the beginning, we used PC tablets from previous studies. Once they were switched on and delivered to the first participants, we detected major failures, and we were forced to substitute these tablets with new ones.
- **Northern Ireland**: Because of the nature of the service being evaluated (increased availability of information to professional care givers via the SCS) there were no technical safety implications.
- **Kinzigtal**: New BS service only caused technical problem, but no risk of safety issues because they did not affect the care treatment itself.

4.4 Discussion of results

The effect on safety, clinical and care effectiveness when introducing ICT supported integrated care for care recipients with multiple co-morbidities and social needs was examined by comparing the difference in number of admissions, the difference in numbers and types of contacts with health and social care providers, and the differences in mortality rates.

Overall, 1,104 care recipients (CRs) were enrolled in the BeyondSilos project; 518 CRs in the intervention group received integrated care (IC), and 586 in the comparator group usual care (UC). Almost 80% of the population completed the full follow-up period. The most common reason for drop outs were: No need for further BS service, deceased, or lost to follow-up. The IC group and the UC group had very similar baseline characteristics. However when comparing the baseline characteristics between sites, some variations were observed in gender distribution, age, social support and primary diseases.

The results of the unadjusted analyses showed that, although the first admission to hospital occurred earlier for IC recipients, their annual admission rate and annual length of hospital stay was significantly lower than for the UC recipients. The IC group also had a significantly lower readmission rate to hospital within 30 days, even though they had a longer follow-up period. The regression analyses showed that a significantly lower number of unplanned hospital admissions were observed for the IC group. However, after adjustments for a number of possible confounders, this difference was no longer found to be statistically significant. No differences in total number of admissions to hospital, total number of days in hospital, or total number of days of unplanned admissions in hospital were observed, which was also confirmed by the confounder adjusted regressions analyses.

More than 37,800 contacts with health and social care professionals were recorded between the two care groups. The overall annual contact rate was found to be significantly lower for the IC group than for UC group. However, after adjusting for confounders, this association was reversed, and the analysis suggested that receiving integrated care was associated with an annual higher contact rate for the IC group than for the UC group. This surprising reversed relationship, which was contrary to prior hypothesis, seemed to be explained by differences in the effect of region, length of follow up (LFU), Charlson Comorbidity Index (CCI) at enrolment, and congestive heart failure as primary disease, which all had a statistically significant effect on the annual contact rate. The annual physical contact rate was found to be significantly lower for the IC group than for UC group, which corresponded with findings that contacts in the IC group were more often conducted by telephone or by home visits, and less often by physical meetings outside of the home compared to the UC group.

Overall, 56 death (5% of the population) were registered in the BeyondSilos project, which was only to be expected given the high age and frail condition of the CRs. No significant difference in the mortality rate between the care groups was observed. There were no technical safety implications of the service.

The overall interpretation of the statistical analyses within the BeyondSilos project may initially suggest that incorporating the BeyondSilos service has not improved the previous situation in terms of effectiveness. However, these findings have to be interpreted cautiously. In order to have the overall picture of the situation within the project, one must keep in mind the large differences in the starting point in terms of integrated care services delivery, differences in number and complexity of components being implemented, and cultural differences in both the care provided and the use of health and social care between the sites. The BeyondSilos project focused on CRs who, because of their advanced age and frail state, were in an elevated need of care, and therefore already consuming a high level of resources before the start of the project. Given their advanced conditions at enrolment, it might be that any beneficial effect that ICT supported integrated care could have on health and social care utilisations was masked by the deterioration associated with a population of frail older people. In other settings where ICT supported integrated care might be used for the delivery of preventive care, the result might be of larger impact, depending on the costs of the service. Some sites reported that the telemonitoring solution was added to the integrated care service in order to have a better understanding of any possible exacerbation over time (between planned contacts). Therefore for them, the key performance indicator regarding technical safety was the main concern, since it was shown that the safety of CRs had not been compromised, the failure to show a reduction in admissions and contacts was not of great concern, since it was expected. It was not possible to include measurements regarding the extent of the new care provided in order to take into account the differences between sites regarding what exactly happened during the new care processes, as compared with usual care, not only in terms of use of ICT, but mainly in interactions / integration of professionals at an individual level. In some sites the difference between IC and UC was not so large, which might explain why no different outcomes were seen. Furthermore, one has to take into account the acknowledged limitations, e.g. variation in data collection method and data quality, different numbers of care recipients, with different characteristics, who have received different services, for different length of follow-up. For a more detailed discussion on methodological consideration and possible biases, please see section 2.5. Lastly, it is important to point out the lack of established key performance indicators for integrated care projects, which is an area that more resources should be focused on, in order to develop and show the true benefit of ICT supported integrated care.

SmartCare & BeyondSilos

The EU project SmartCare (SmartCare 2016), which ended in August 2016, also examined whether implementing ICT supported integrated health and social care would reduce the number of admissions to hospital and the number of contact to health or social care. In that project, they found that CRs from the IC group were less likely to be hospitalised, less likely to have unplanned hospitalisation, but had more contacts with health and social care professionals. No significant differences in days in hospital or number of admissions per care recipients were found. Similar finding regarding an increased number of contacts with health and social care professionals in the IC group were also found in the BeyondSilos project. In the SmartCare project, it was argued that in the first months of a new service, more contacts are necessary in order to better understand the pathway and how it works. Very often some technical issues could also arise, which need some contacts in order to be solved. This issue was also discussed in the BeyondSilos project, especially after the sites were asked to provide log-files of the use of the shared care platforms and some differences were observed. In SmartCare, difficulties in replacing the physical meeting between CRs and the health or social care providers were reported. In BeyondSilos, the annual physical contact rate was found to be significantly lower for the IC group than for UC group, which corresponded with findings that contacts in the IC group were more often conducted by telephone or by home visits, and less often by physical meetings outside of the home compared to the UC group. This might indicate that the BeyondSilos service was successful in changing the type of contacts away from physical meetings, which potentially could have an economic benefit.

The BeyondSilos project could not confirm the findings of fewer hospital admissions and unplanned hospitalisation in the SmartCare project, which might be due to differences in the two populations examined. In SmartCare few inclusion criteria were applied, whereas BeyondSilos tried to secure a more homogeneous population by making restrictions regarding age, health condition and presence of social needs. Under-reporting of contacts due to significant difficulties in data collection and technical problems with data upload seems to be a generic problem for both projects, which also could have affected the results. The same statistical team performed the statistical analyses for both projects. They stated that the BeyondSilos data were more homogeneous than the data in SmartCare, e.g. in relation to age, gender and primary diseases and co-morbidities, which indicated that the results of BeyondSilos have the potential to be more robust. However, due to the commonalities in project objectives and outcome measures, it would be interesting to combine data from the two projects in order to perform stratified analyses on a larger and more robust population.

4.5 Summary

- The primary research hypothesis of the project was that BeyondSilos would improve care recipients' perspectives, mainly emotional well-being, functional capability and satisfaction, while at the same reducing their need for hospital admission and contacts with health and social care providers.
- Overall, 1,104 care recipients (CR) were enrolled in the BeyondSilos project; 518 CR in the intervention group received integrated care (IC), and 586 in the comparator group usual care (UC).
- Almost 80% of the population completed the full follow-up period.
- More CRs were lost to follow-up in the IC group than in the UC group. However, the IC group were also followed for a longer period than the UC group.
- The IC group and UC group had very similar baseline characteristics. However when comparing the baseline characteristics between sites, some variations were observed in gender distribution, age, social support, and primary diseases.
- More than half of CRs were female, and more than 80% were more than 75 years old.
- Around 60% of the CRs had received some kind of social support (most often logistic support such as meals, cleaning) at the beginning of the BeyondSilos project.
- Although the first admission to hospital occurred earlier for the IC group, unadjusted analyses suggested that their annual admission rate and annual length of hospital stay were significantly lower than for the UC group.
- The IC group had a lower readmission rate to hospital within 30 days even though they had a longer follow-up period.
- The regression analyses showed that a significantly lower number of unplanned hospital admissions were observed for the IC group. However, after adjustments for a number of possible confounders, this difference was no longer found to be statistically significant.
- No differences in total number of admissions to hospital, total number of days in hospital, or total number of days of unplanned admissions in hospital were observed, which was also confirmed by the confounder adjusted regressions analyses.

- An increased annual number of contacts with health and social care professionals was reported. However, these findings have to be interpreted cautiously, because of a number of limitations, e.g. different number of CRs, significantly different care groups, different length of follow-up, small sample sizes, etc. The individual site level analyses showed a significant reduction in the annual contact rate for three of the sites.
- Fewer annual physical contacts were registered in the IC group than in the UC group, which corresponded with findings that contacts in the IC group were more often conducted by telephone or by home visits, and less often by physical meetings outside of the home compared to the UC group.
- In at least some sites, expected outcomes were achieved, such as fewer contacts with the health and social care professionals in intervention group compared with control group (usual care).
- BeyondSilos services were safe from a clinical and technical point of view; there was no statistical significant difference in mortality.
- Due to the diversity seen in the project, site level evaluations are considered extremely important; the full reports are attached as annexes in this document. These are considered the basic elements of the project level evaluation.
- A number of challenges have been clearly acknowledged during the project and considered as the starting point for this evaluation. Most of these challenges are due to the fact that the project has been conducted in real life conditions, and had to deal with the major differences that exist in the way care is organised in different regions, and with very different starting situations between one region and another. These challenges includes:
    - Recruiting participants: Several sites reported difficulties in recruiting care recipients, especially for the IC group. Reasons for this were, among others, scepticism by both CRs and family members towards having or using tele health solutions in their homes. Some sites also reported that the inclusion criteria had a limiting effect in reaching recruitment numbers.
    - Allocation of care recipients to care group: Prior to enrolling CRs in the BeyondSilos project, all sites had planned how to allocate CRs to either the integrated care group or the usual care group. However, most pilot sites experienced that due to difficulties in the recruitment process, a strict randomisation or matching process was not possible.
    - We have to acknowledge that our wish to collect as much and diverse data as possible with repeated measurements (start, mid, end) might have had a negative effect on the response rate of the study population. Their old age and frail condition might have contributed to a reluctance to answer some questions, therefore introducing missing answers.
- Due to the above mentioned challenges it is recommended that in future projects, more emphasis should be put into supporting and guiding sites in the recruitment phase, measurements, data collection, upload to a central web database, and data analyses.
- It is important to define the sample size of people to be enrolled in the new services in proportion to real work capacity of the services / professionals. This also to plan adequately ICT provision.
- The lack of established key performance indicators for integrated care projects is an area that more resources should be focused on, in order to develop and show the true benefit of ICT supported integrated care.

5 Domain 4: Care recipient perspectives

5.1 Introduction:

Domain 4 of the MAST evaluation consisted of a combination of the results of the quantitative aspects of care recipient (CR) social needs derived from the Barthel Index[27] [28] and the Instrumental Activities of Daily Living (IADL) [29] scale, and their emotional state assessed by the Geriatric Depression Scale (GDS). Aspects of the CRs' satisfaction with the new integrated care service were assessed by examining selected questions from the questionnaire on users' experiences of integrated care (PIRU) and from the eCare Client Impact Survey (eCCIS), alongside any additional input from the local process evaluations where a number of CRs were interviewed.

5.2 Social needs

Social needs are assessed by measuring functional capabilities, which refers 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 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 everyday life, such as eating, bathing, dressing, toileting, and moving around, and instrumental activities of daily living (IADLs), which include basic activities necessary to reside in the community such as handling personal finances, meal preparation, shopping, travelling, doing housework, using the telephone, and taking medication. In general, IADL disabilities represent less severe dysfunction than ADLs.

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 and IADLs, prevalence rates are much higher for the elderly than for the non-elderly. Within the elderly population, the prevalence rates rise steeply with advancing age, and are especially high for persons aged 85 and over. Measurement of ADLs and IADLs are critical, because they have been found to be significant predictors of mortality, use of healthcare services (hospital or physician services, GPs visits, home care, etc.), and admission to a nursing home.

Acting on the belief that ICT supported integrated care service could assist CRs in coping with their daily life activities, we hypothesised that the new ICT supported integrated care service would have a beneficial effect on the response to social needs of the care recipients, with a probable positive impact on the "natural history" of their medical conditions. In these elderly people suffering from chronic diseases and co morbidities, joint integrated actions should lead to more comprehensive treatment of health issues, so that the expected deterioration could be slowed down by the new service.

5.2.1 Barthel Index

The Barthel index is used to measure performance in activities of daily living (ADL). It was introduced in 1965, and yielded a score of 0–20. Although this original version is still widely used, it was modified by Granger et al. in 1979, when it came to include 0–10 points for every variable, and further refinements

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[27] Mahoney FI, Barthel D. “Functional evaluation: the Barthel Index.” Maryland State Medical Journal 1965;14:56-61

[28] 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

[29] 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.

were introduced in 1989. The modified Barthel index was designed as the original scale was insensitive to change and had arbitrary scores. The sensitised version sharply discriminates between good and better and poor and poorer performances. Its effectiveness is not just with in-patient rehabilitation but home care, nursing care, skilled nursing, and community. The Barthel index has been shown to have portability, and has been used in 16 major diagnostic conditions. The Barthel index has demonstrated high inter-rater reliability (0.95) and test–retest reliability (0.89), as well as high correlations (0.74–0.8) with other measures of physical disability[30].

5.2.1.1 Assessment methodology

The Barthel index uses ten variables describing ADL and mobility used to measure performance in activities of daily living (ADL) (see Appendix E.1). Each performance item is rated on a scale with a given number of points assigned to each level or ranking. A higher number is associated with a greater likelihood of being able to live at home with a degree of independence following discharge from hospital. The amount of time and physical assistance required to perform each item are used to determine the assigned value of each item. External factors within the environment affect the score of each item. If adaptations outside the standard home environment are met during assessment, the participant’s score will be lower if these conditions are not available. If adaptations to the environment are made, they should be described in detail and attached to the Barthel index.

5.2.2 Instrumental Activities of Daily Living Scale

The Lawton Instrumental Activities of Daily Living (IADL) scale is an appropriate instrument to assess independent living skills[31] (see Appendix E.2). This assessment instrument is widely used both in research and clinical practice. These skills are considered more complex than the basic activities of daily living as measured by the Barthel Index. Few studies have been performed to test the Lawton IADL scale psychometric properties. The Lawton IADL Scale was originally tested concurrently with the Physical Self-Maintenance Scale (PSMS). Reliability was established with twelve subjects interviewed by one interviewer with the second rater present but not participating in the interview process. Inter-rater reliability was established at 0.85. The validity of the Lawton IADL was tested by determining the correlation of the Lawton IADL with four scales that measured domains of functional status, the Physical Classification (6-point rating of physical health), Mental Status Questionnaire (10-point test of orientation and memory), Behaviour and Adjustment rating scales (4-6-point measure of intellectual, person, behavioural and social adjustment), and the PSMS (6-item ADLs). A total of 180 research subjects participated in the study; however, few received all five evaluations. All correlations were significant at the 0.01 or 0.05 level.

5.2.2.1 Assessment methodology

The Instrumental Activities of Daily Living Scale measures eight domains of functions (see Appendix E.2). Each performance item is rated on a scale with a given number of points assigned to each level or ranking. Persons are scored according to their highest level of functioning in that category. A summary score ranges from 0 (low function, dependent) to 8 (high function, independent).

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[30] References:
[1] Mahoney FI, Barthel DW. Functional Evaluation: The Barthel Index. Maryland State Med J 1965; 14: 61–5
[2] Report of joint workshops of the Research Unit of the Royal College of Physicians and the British Geriatrics Society. Standardised assessment scales for elderly people. London: Royal College of Physicians 1992
[3] Collin C, Wade D. The Barthel Index: a reliability study. Int Disabil Stud 1988; 10: 61–3

[31] 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

The instrument is most useful for identifying how a person is functioning at the present time and for identifying improvement or deterioration over time. This instrument is intended to be used among older adults, and may be used in community, clinic, or hospital settings. The instrument is not useful for institutionalised older adults. It may be used as a baseline assessment tool, and to compare baseline function with periodic assessments. To avoid potential gender bias at the time the instrument was developed, specific items were omitted for men. Historically, women were scored on all eight areas of function; men were not scored in the domains of food preparation, housekeeping, laundering. However, current recommendations are to assess all domains for both genders[32].

5.2.3 Methodology: Analyses of functional capability

To assess the functional capability of CRs enrolled in the BeyondSilos project, and possible changes over the life span of the project, the performance in activities of daily living (ADLs, measured by the Barthel scale) and the instrumental activities in daily life (IADL) was measured at enrolment and at the end of the evaluation period for the CRs. Differences in changes in the BI score and the IADL score from enrolment to the end of follow-up, and between the two care groups, were assessed by logistic regression analyses.

5.2.4 Findings on performance in activities of daily living (BI)

Table 20 presents the mean Barthel Index score for the integrated care group and the usual care group at enrolment and at the end of the evaluation period, together with the changes from enrolment to the end of the evaluation period for both care groups. A higher score is associated with a greater degree of independence.

The results showed that the IC group had a lower BI score at the enrolment than the UC group (IC 57.42 vs UC 70.76) indicating a higher degree of dependency in the IC group compared to the UC group.

The IC group seemed to have an increase in the BI score (0.6) at the end of the follow-up period (indicating an increase in independence) whereas the UC group had a deterioration in the BI score (-1.36) (indicating a decline in independence). However, the changes observed for both groups were small and not significant.

At a site level, there were large differences in the BI score at enrolment. In Campania, the BI score at enrolment was 10.75 for IC group and 21.11 for UC group whereas for Sofia and Valencia the BI score was above 80 for both groups. Significant deterioration of the BI score was observed for both care groups in Valencia and for the comparator groups of Kinzigtal and Badalona. A significant increase in the BI score was observed for the IC group in Amadora and the UC group of Sofia. Only Sofia showed a significant change in the BI score between the care groups, where a larger increase in the BI score of the UC group was observed compared to the IC group indicating a negative effect of the intervention group.

Table 20: Impact on Barthel index by care group

Measurement	Integrated care Group	Usual care group	Unadjusted BeyondSilos effect
(N=643)	**Mean (SD)**	**Mean (SD)**	
Enrolment	57.42 (33.62)	70.76 (31.48)	
End	58.02 (33.99)	69.4 (31.02)	
Change	0.6 (-1.05, 2.24)	-1.36 (-2.58, -0.15)	1.96 (-0.08, 4.00)
p value	*0.331*	*0.929*	*0.060*

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[32] Lawton MP, Moss M, Fulcomer M, & Kleban MH (2003). Multi-level assessment instrument manual for full-length MAI. North Wales PA: Polisher Research Institute, Madlyn and Leonard Abramson Centre for Jewish Life

Multiple linear regression analysis (Table 21) with care group as the exposure and average change over time in the BI score as the outcome showed that the score improved for 1.96 units (95%CI: -0.19, 4.10), for the IC group compared to the UC group, indicating a greater increase in independence for the IC group. However, this difference was not statistically significant, considering no other confounders. When adjusting for the possible confounders (care group, gender, age, Charlson Comorbidity Index (CCI) at the enrolment, Length of Follow-up (>=90days included), primary disease, region and Barthel Index at enrolment), this trend was further weakened and still not statistically significant (b=1.36, 95%CI: -0.18-2.90).

At site level, the regression analyses showed that after adjusting for possible confounders, a significant improvement in the BI score was observed for the IC group compared to the UC group for Kinzigtal (b=15.04, 95%CI: 6.71-23.37) and a significant negative effect of the IC group compared to the UC group was observed for Sofia (b=-3, 95%CI: -5.76- -0.25).

Table 21: Impact on Barthel Index by care group presented as unadjusted and adjusted results

Difference in Barthel Index	**Unadjusted Effect size (95% CI)**	**Confounder adjusted** Effect size (95% CI)**
Intervention	b =1.96, (95%CI: -0.19, 4.10), p = 0.074 [a]	b=1.36, (95%CI: -0.18, 2.90), p = 0.082 [a]
Control	reference	reference

a Multiple linear regression; * Statistically significant result

** Adjusted for care group, gender, age, Charlson Comorbidity Index (CCI) at the enrolment, Length of Follow-up (>=90days included), primary disease, region and Barthel Index at enrolment.

5.2.5 Findings on instrumental activities of daily living (IADL)

Table 22 presents the mean Instrumental Activities of Daily Living Scale (IADL) score for the integrated care group and the usual care group at enrolment and at the end of the evaluation period, together with the change in the IADL score from enrolment to the end of the evaluation period for both care groups. A higher score indicates a higher level of independence.

The results shows that the IC group had a lower IADL score at the enrolment than the UC group (IC 3.04vs UC 3.64) indicating a higher degree of dependency in the IC group compared to the UC group. Both care groups had a deterioration in the IADL score at the end of the follow-up period. However, the changes observed for both groups were small and not significant.

Table 22: Impact on Instrumental Activities of Daily Living Scale (IADL) Score by care group

Measurement	**Intervention Group**	**Comparator Group**	**Unadjusted BeyondSilos effect**
N=640			
Enrolment	3.04 (2.72)	3.64 (2.74)	
End	2.97 (2.69)	3.61 (2.86)	
Change	-0.06 (-0.21, 0.08)	-0.03 (-0.16, 0.10)	-0.03 (-0.23, 0.16)
p value	0.385	0.681	0.705

Quantitative data presented as mean (SD), unless otherwise indicated.

* Statistically significant p-value (p<0.05)

Multiple linear regression analysis (Table 23) with care group as the exposure and average change over time in the IADL score as the outcome showed that care recipients from the IC group were significantly more likely to have a decrease in the IADL score (higher level of dependence) than CR from the UC group (unstandardised coefficient B [b] for IC vs UC = -0.26, 95% confidence interval [CI] = -0.42, 0.09), after adjusting for possible confounders (care group, gender, age, Charlson Comorbidity Index (CCI) at the enrolment, Length of Follow-up (>=90days included), primary disease, region and IADL score at enrolment). Gender, age, region and IADL score at enrolment were found to have a statistically significant effect on the difference of IADL score before and after the study.

At site level, large differences in the IADL score at enrolment were observed. The lowest IADL scores were observed in Campania, where both care groups had an IADL score below 1.25; but this was because all care recipients in Campania were home hospitalised and receiving intensive care. The highest scores were observed in Sofia where the IADL score were above 6.6 for both care groups. Sofia showed a significant increase in the IADL score for both care groups; however, the increase for the UC group was significantly higher than the increase for the IC group, which was confirmed by the confounder adjusted logistic regression analysis, indicating a negative effect of the intervention group.

A significant deterioration of the IADL score was observed for both care groups in Badalona, however no significant difference between the changes in the two care groups was observed, which was confirmed by the confounder adjusted logistic regression analysis. A significant increase in the BI score was observed for the IC group in Amadora.

Table 23: Impact on Instrumental Activities of Daily Living scale by care group presented as unadjusted and adjusted results

Difference in change in Instrumental Activities of Daily Living Scale (IADL)	**Unadjusted Effect size (95% CI)**	**Confounder adjusted** Effect size (95% CI)**
Integrated care	b=-0.03, (95%CI: -0.23, 0.17), p = 0.751 a	b=-0.26, (95%CI: -0.42, 0.09), p < 0.05 *a
Usual care	reference	Reference

a Multiple linear regression; * Statistically significant result

** Adjusted for care group, gender, age, Charlson Comorbidity Index (CCI) at the enrolment, Length of Follow-up (>=90days included), primary disease, region and IADL score at enrolment.

5.2.6 Discussion of findings

We assessed the changes in the care recipient's functional capability (as measured by activity of daily living (Barthel Index) and Instrumental Activity of Daily Living) over the follow-up period in both the IC group and UC group. The measure of functional capability was used as a proxy for social needs. The sample consisted of CRs with a length of follow-up exceeding 90 days. The analyses indicated that CRs in the IC group had a lower functional capability at enrolment than CRs in the UC group. This tendency was observed for both BI and IADL scores. The confounder adjusted multiple linear regression analysis of the change in BI score between the two care groups showed a small improvement in the independence of activity of daily living at the end of the follow-up period for the IC group compared to the UC group. However, this difference was not found to be statistically significant. The confounder adjusted multiple linear regression analysis of the change in IADL score between the two care groups showed a significantly decrease in the IADL score indicating a larger decrease in independence in the IC group compared to the UC group at the end of the follow-up period.

In the context of BeyondSilos, functional capability was used as an indication for social needs. The measurements were used in the assessment of eligibility of care recipients in the enrolment process, but also as an additional secondary outcome measure to assess the effectiveness of the integrated care programme. Acting on the belief that the new ICT supported integrated care service could assist CRs in coping with their daily life activities, we hypothesised that the new ICT supported integrated care service would have a beneficial effect on the social needs of the care recipients, with a positive impact on the development of their medical conditions, so that the expected deterioration could be slowed down by the new service. However, the analyses of the functional capability did not confirm this hypothesis for the assessment of either BI or IADL. To our surprise, the analyses showed a significantly higher deterioration in the instrumental activity of daily living (IADL) throughout the follow-up period for the IC group compared to the UC group, and no significantly change in the independence of activities of daily living (BI) between the care groups throughout the follow-up period.

Prior studies[33] have stated that the IADL score is most useful for identifying how a person is functioning at the present time, and for identifying improvement or deterioration over time. This explain why a difference between groups was only observed for the IADL score.

A study[34] assessing the functional and cognitive changes exhibited by the elderly over a 6-month period found that a reduction of the participants' functional instrumental activities of daily living were associated with living alone, work status and cognitive function. In the BeyondSilos project, we collected data on marital status, longest held occupation and a long list of co-morbidities which among others included dementia, which is related to cognitive status. It was not possible to include these variables in the statistically analyses due to the size of the dataset. However, a comparison between the baseline measurements of the two care groups did not show any differences in the distribution of the variables between the IC group and the UC group.

A lower functional capability score at enrolment was found to have a statistically significant negative effect on the change in functional capability at the end of the follow-up period for both the BI score and IADL score. Since a lower independence level was measured for both ADL and IADL in the IC group compared to the UC group at enrolment, this might explain the unexpected result.

It cannot be ruled out that missing or inaccurate reporting of data has occurred, and that this might have affected the results. For example, if a more thorough examination of the functional capability was performed among the IC group, it could result in reporting lower BI and IADL scores in this group compared to the UC group, and that any deterioration observed might be associated with deteriorating health in a population of frail older people, and not with the service provided. Lastly, the large variation of BI score and IADL scores observed between the sites, and also between the IC group and the UC group, might raise the question as to how comparable the sites and the comparison groups actually are, even though a comparison of baseline characteristics suggest comparability.

5.3 Geriatric Depression Scale

Depression is not a natural part of aging. Depression is often reversible with prompt recognition and appropriate treatment. However, if left untreated, depression may result in the onset of physical, cognitive, functional, and social impairment, as well as decreased quality of life, delayed recovery from medical illness and surgery, increased healthcare utilisation, and suicide. While there are many instruments available to measure depression, the Geriatric Depression Scale (GDS), first created by Yesavage, et al.[35], has been tested and used extensively with the older population. The GDS Long Form is

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[33] 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

[34] Figueiredo CS, Assis MG, Silva SLA, Dias RC, Mancini MC. Functional and cognitive changes in community-dwelling elderly: longitudinal study. Braz J Phys Ther. 2013 May-June; 17(3):297-30

[35] Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M.B., & Leirer, V.O. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. Journal of Psychiatric Research, 17, 37-49.

a 30-item questionnaire in which participants are asked to respond by answering yes or no in reference to how they felt over the past week. A Short Form GDS consisting of 15 questions was developed in 1986[36]. Questions from the Long Form GDS which had the highest correlation with depressive symptoms in validation studies were selected for the short version. Of the 15 items, 10 indicate the presence of depression when answered positively, while the rest (questions 1, 5, 7, 11, 13) indicate depression when answered negatively. Scores of 0-4 are considered normal, depending on age, education, and complaints; 5-8 indicate mild depression; 9-11 indicate moderate depression; and 12-15 indicate severe depression.

The Short Form is more easily used by physically ill and mildly to moderately demented patients who have short attention spans and/or feel easily fatigued. It takes about 5 - 7 minutes to complete. It has been extensively used in community, acute and long-term care settings. The GDS was found to have a 92% sensitivity and a 89% specificity when evaluated against diagnostic criteria. The validity and reliability of the tool have been supported through both clinical practice and research. In a validation study comparing the Long and Short Forms of the GDS for self-rating of symptoms of depression, both were successful in differentiating depressed from non-depressed adults with a high correlation ($r = .84$, $p < .001$)[37].

5.3.1 Assessment methodology

The GDS questions are answered "yes" or "no" (see Appendix E.3). This simplicity enables the scale to be used with ill or moderately cognitively impaired individuals. The scale is commonly used as a routine part of a comprehensive geriatric assessment.

One point is assigned to each answer and the cumulative score is rated on a scoring grid. Answers in bold indicate depression. Score 1 point for each bolded answer. The final score is the tally of the number of depressive answers with the following scores indicating depression.

0 – 4	No depression.
5 – 10	Suggestive of a mild depression.
11–15	Suggestive of severe depression.

A score > 5 points should warrant a follow-up comprehensive assessment[38].

5.3.2 Findings on depression

Whereas the IC group seemed to have a small increase in the depression score at the end of follow up, the UC group had a significantly decrease in the depression score at the end of the follow-up period.

Table 24 displays the mean Geriatric Depression Scale (GDS) score for the IC group and the UC group at enrolment and at the end of the evaluation period, together with the change in the GDS score from enrolment to the end of the evaluation period for both care groups. A higher score indicates a higher risk of depression; note that a score > 5 points is suggestive of depression, while scores > 10 are almost always depression. The results showed that the IC group had a higher score of depression at enrolment than the UC group (IC 5.87 vs UC 5.41) indicating a higher degree of depression in the IC group compared to the UC group. Whereas the IC group seemed to have a small increase in the depression score at the end of follow up, the UC group had a significantly decrease in the depression score.

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[36] Sheikh, J.I., & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS). Recent evidence and development of a shorter version. In T.L. Brink (Ed.), Clinical Gerontology: A Guide to Assessment and Intervention (pp. 165-173). NY: The Haworth Press, Inc.

[37] Sheikh & Yesavage, 1986

[38] Source: http://www.stanford.edu/~yesavage/GDS.html

Table 24: Impact on Geriatric Depression Scale (Short Form) per care group

Measurement	Intervention Group	Comparator Group	Unadjusted BeyondSilos effect
N=615			
Enrolment	5.87 (3.69)	5.41 (3.56)	
End	6.19 (3.45)	4.89 (3.33)	
Change	0.32 (-0.02, 0.65)	-0.53 (-0.88, -0.17)	0.84 (-0.35, 1.33)
p value	*0.060*	*0.021**	*0.001***

Quantitative data presented as mean (SD), unless otherwise indicated.
* Statistically significant p-value (p<0.05)
** Statistically significant p-value (p<0.01)

Multiple linear regression analysis with care group as the exposure and average change over time in the GDS score as the outcome (Table 25) showed that CRs from the IC group were more likely to have a statistically significant deterioration of the GDS score (worsening of the depression symptoms) than CRs from the UC group (unstandardised coefficient B [b] for IC vs UC = 0.63, 95% confidence interval [CI] = 0.18 - 1.08), after adjusting for possible confounders (care group, gender, age, Charlson Comorbidity Index (CCI) at enrolment, length of follow-up (>=90days included), primary disease, region and GDS score at enrolment). The confounders Region and GDS score at enrolment had a statistically significant effect on the difference of GDS score before and after the study.

At site level, a large difference in the mean GDS score at enrolment was observed. The mean GDS score in the IC group at enrolment ranged from 2.52 in Kinzigtal to 7.23 in Badalona, and the mean GDS score in the UC group at enrolment ranged from 3.76 in Valencia to 6.11 in Badalona. Even though the overall project level GDS score was higher in the IC group than in the UC group at enrolment, this was only the case in two sites (Badalona and Campania); for the rest of the sites the trend was reverse. At the end of the follow-up period, Sofia had a significant decrease in the GDS score for both care groups, and Northern Ireland had a significant decrease in the GDS score for the IC group, whereas Amadora observed a significant increase in GDS score for the IC group. The confounder adjusted logistic regression analysis confirmed a significant increase in the GDS score for the IC group compared to the UC group (b=0.76, 95%CI: 0.06-1.46).

Table 25: Impact on Geriatric Depression Scale (Short Form) per care group presented as unadjusted and adjusted results

Difference in Geriatric Depression Scale (GDS) score	Unadjusted Effect size (95% CI)	Confounder adjusted** Effect size (95% CI)
Intervention	b=0.84[2], (95%CI: 0.35, 1.33), p < 0.001 *a	b=0.63[2], (95%CI: 0.18 - 1.08), p < 0.05 *a
Control	reference	reference

a Multiple linear regression.
* Statistically significant result.
** Adjusted for care group, gender, age, Charlson Comorbidity Index (CCI) at the enrolment, Length of Follow-up (>=90days included), primary disease, region and GDS score at enrolment.
2 b= Unstandardised Coefficient B (If the regression beta coefficient is positive, the interpretation is that for every 1-unit increase in the predictor variable, the dependent variable will increase by the unstandardised beta coefficient value.)

5.3.3 Discussions of findings

We assessed the changes in the care recipient's psychological wellbeing, as measured by Geriatric Depression Scale (GDS), over the follow-up period in both the IC group and the UC group. The sample consisted of CRs with a length of follow-up exceeding 90 days. The analyses indicated that CRs in the IC group had a greater degree of depression at enrolment than CRs in the UC group. The confounder adjusted multiple linear regression analysis of the change in GDS score between the two care groups showed a significant larger increase in the depression symptoms for the IC group compared to the UC group at the end of the follow-up period when taking into account care group, gender, age, Charlson Comorbidity Index (CCI) at the enrolment, Length of Follow-up (>=90days included), primary disease, region, and GDS score at enrolment.

In the context of BeyondSilos, the measurement of depression was used as an indication of changes in psychological wellbeing. The measurement was used as an additional secondary outcome measure to assess the effectiveness of the integrated care programme. Acting on the believe that the new ICT supported integrated care service could make the care recipients feel safer, better taken care of, and more in control of their own condition, we hypothesised that the service would have a beneficial effect on the psychological wellbeing of the care recipients which would be reflected by a positive change in the GDS score for the CRs receiving IC (either a larger decrease or a smaller increase in the GDS score compared to the UC group). To our surprise, the analyses showed a significantly higher increase in the depression symptoms throughout the follow-up period for the IC group compared to the UC group.

The GDS was carefully selected as a measurement tool to match the older population targeted in the BeyondSilos project, since studies had shown that the GDS scale is useful to assess depressive symptoms among very old people, also above 85 years[39,40]. The GDS tool has been validated in many European countries, and translated into all the languages spoken in the BS sites. However, several sites, especially Valencia, reported that a large number of the questions were considered intrusive and not relevant for some of the CRs, which led either to missing answers or neutral replies. The sites therefore discussed whether CRs in the BeyondSilos project might be too old and frail for questions regarding their view of life (e.g. "Do you feel that your life is empty?" or "Do you think it is wonderful to be alive?") to reflect differences in occurrence of depression rather than an indication of a general life view at the end of a long life with chronic diseases and low functional capability. It also raised the discussion of the importance of training the interviewers thoroughly to ask these sensitive questions so that they would not be imposing their own prejudices on CRs, or refrain from asking delicate questions and inadvertently introducing errors into the measurement. It cannot be ruled out that missing or inaccurate reporting of data might have affected the results, especially if such a measurement error was systemic. If a more thorough GDS examination was performed among the IC group, it could result in reporting of higher GDS scores in this group compared to the UC group. In this case, any deterioration observed might be due to measurement errors in the comparator group, and not a reflection of the integrated service provided.

A higher GDS score at the enrolment was found to have a statistically significant negative effect on the change in GDS score at the end of the follow-up period. More severe depression symptoms were measured for the IC group compared to the UC group at enrolment, which might explain the unexpected result. Lastly, the large variation of GDS scores observed between the sites, and also between the IC group and the UC group at enrolment, might raise the question of how comparable the sites and the comparison groups actually are even, though an assessment of baseline characteristics suggest comparability.

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[39] Conradsson M, Rosendahl E, Littbrand H, Gustafson Y, Olofsson B, Lövheima H. Usefulness of the Geriatric Depression Scale 15-item version among very old people with and without cognitive impairment. Aging Ment Health. 2013 Jul; 17(5): 638–645.

[40] Blazer, D.G. (2009). Depression in late life: Review and commentary. FOCUS, 7(1), 118-136

5.4 Care satisfaction

In the context of BeyondSilos, selected questions from the PIRU questionnaire on user experience of integrated care and the eCare Client Impact Survey (eCCIS) were used to shed light on the user experience of integrated care performance. The answers given by the CR were analysed narratively.

5.4.1 PIRU user experience on integrated care

The PIRU questionnaire on user experience of integrated care was developed by the Picker Institute and Oxford University, and first published in January 2014, in their report: Developing measures of people's self-reported experiences of integrated care, commissioned by the Department of Health in May 2013. PIRU is a novel collaboration between the London School of Hygiene & Tropical Medicine (LSHTM), the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE), and the Health and Care Infrastructure Research and Innovation Centre (HaCIRIC) at Imperial College London Business School plus RAND Europe and the Nuffield Trust[41].

The PIRU questionnaire provides 18 questions that were derived from the National Voices integrated care 'I statements' and tested with patients, social care service users and carers[42].

Since the PIRU questionnaire has been developed in English, and so far has not been translated or validated in any other languages, the sites of BeyondSilos translated the questions themselves after agreement with the Picker Institute. In the case of Valencia (Spain) and Badalona (Spain), it was arranged that one site translated the questions into Spanish while the other site did a back translation into English as a validation. The same arrangement was done for Campania (Italy) and the site ULSS N.2 Feltre (Italy) involved in the CareWell project. All other sites were encouraged to perform a translation / back translation internally.

In the context of BeyondSilos, the sites decided to make it mandatory to answer only two of the questions from the PIRU questionnaire on user experience of integrated care. The reason was that the new integrated service was not visible to all CRs, and therefore applying the full questionnaire for all CRs would not result in any meaningful input to the evaluation, but would have the potential to cause confusion.

The following two questions from the PIRU questionnaire on user experience of integrated care were assessed:

- To what extent do you agree or disagree with the following statement…'Health and social care staff always tell me what will happen next'.
- Do all the different people treating and caring for you work well together to give you the best possible care and support?

5.4.2 eCare Client Impact Survey (eCCIS)

Aspects of client satisfaction were measured using the eCare Client Impact Survey. The instrument was originally developed by WRC (Work Research Centre) in collaboration with empirica in the CommonWell project (www.commonwell.eu) and further refined in the INDEPENDENT project (www.independent-project.eu). For exemple results of its use, see the final outcome reports of both projects.

eCCIS primarily measures how care recipients (clients, patients) perceive the utility of an e-Care service. The construct of *perceived service utility* is broken down into specific service-related impacts on the one

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[41] Reference: http://www.piru.ac.uk/assets/files/IC%20and%20support%20Pioneers-Indicators.pdf

[42] Reference: http://www.pickereurope.org/integrated-care/).

hand, and a summary assessment on the other, each addressed with one question module. For CRs, the specific service-related impacts module covers the areas of physical capacity, mental wellbeing, living with health conditions and social relations. Each area is in turn addressed by one or more questions, asking respondents to rate the extent to which the intervention under evaluation has affected them. The rating is expressed on a 5-point Likert-type scale, ranging from a very positive impact to a very negative impact. The summary assessment module covers overall satisfaction with the service, whether the service is worth the effort involved in using it, and whether the respondent would want to continue using the service or to use it again. The instrument was applied retrospectively, when the respondent left the evaluation or the service.

In the context of BeyondSilos, the eCCIS was used to feed information into the ASISST tool used for the cost-benefit analysis (see domain 5, section 6), and therefore only applied to CRs receiving the new treatment. However, we thought that the responses to one of the eCCIS questions could be useful when assessing the CR's experience of the service they were receiving, and comparing the answer between the IC and the UC groups.

The following question from the eCCIS was applied to both care groups:

- When it comes to information about your health and well-being, do you feel that you have to repeat this information a lot when talking to different people treating and caring for you?

The additional questions from the eCCIS were only applied to the IC group. We used the answers to these questions to encapsulate and analyse in a descriptive way the IC recipients' satisfaction and opinion with the new service at the time when the evaluation was about to finish. Note that since these questions have not been applied to CRs receiving usual care, a comparison between care groups was not possible.

5.4.3 Findings on PIRU user experience of Integrated Care

Table 26 presents the answers given by CRs to the two selected question of the PIRU questionnaire on user experience of integrated care. Answers to the full questionnaire can be seen in the annexes for the Valencia, Badalona, Amadora and Sofia sites.

Overall, more than 75% of CRs answered that they *agreed* or *strongly agreed* with the question "Health and social care staff always tell me what will happen next" (79% for the IC vs 76% for the UC). At the end of follow-up, 81% of CRs in the IC group *agreed* or *strongly agreed* with the statement compared to 76% in the UC group.

In relation to the question "Do all the different people treating and caring for you work well together to give you the best possible care and support?", 84% of CRs in both care groups answered that they *agreed* or *strongly agreed* at the time of enrolment. At the end of follow-up, 86,5% of the CRs in the IC group *agreed* or *strongly agreed* with the statement compared to 81,5% in the UC group.

Table 26: PIRU results

	Integrated care group		Usual care group		P-valua	Total	
	N	%	N	%		N	%
To what extent do you agree or disagree with the following statement…'Health and social care staff always tell me what will happen next'							
Assessment at enrolment							
Strongly agree	174	38.2%	213	42.3%	0.056	387	40.4%
Agree	186	40.8%	169	33.6%		355	37.0%
Neither agree nor disagree	67	14.7%	91	18.1%		158	16.5%
Disagree	27	5.9%	23	4.6%		50	5.2%
Strongly disagree	2	0.4%	7	1.4%		9	0.9%
Assessment at end of follow-up							
Strongly agree	163	42.0%	96	33.9%	0.130	259	38.6%
Agree	152	39.2%	120	42.4%		272	40.5%
Neither agree nor disagree	65	16.8%	60	21.2%		125	18.6%
Disagree	6	1.5%	7	2.5%		13	1.9%
Strongly disagree	2	0.5%	0	0.0%		2	0.3%
Do all the different people treating and caring for you work well together to give you the best possible care and support?							
Assessment at enrolment							
Strongly agree	247	54.3%	314	62.7%	0.017	561	58.7%
Agree	134	29.5%	106	21.2%		240	25.1%
Neither agree nor disagree	37	8.1%	48	9.6%		85	8.9%
Disagree	23	5.1%	16	3.2%		39	4.1%
Strongly disagree	14	3.1%	17	3.4%		31	3.2%
Assessment at end of follow-up							
Strongly agree	200	51.8%	142	50.5%	0.347	342	51.3%
Agree	134	34.7%	87	31.0%		221	33.1%
Neither agree nor disagree	42	10.9%	44	15.7%		86	12.9%
Disagree	3	0.8%	1	0.4%		4	0.6%
Strongly disagree	7	1.8%	7	2.5%		14	2.1%

5.4.4 Findings on eCare Client Impact Survey

Table 27 presents the answers given at enrolment and at the end of the evaluation period for both care groups to the question "When it comes to information about your health and well-being, do you feel that you have to repeat this information a lot when talking to different people treating and caring for you?" The distribution of answers shows that around 14% of CRs in both groups felt that they had to repeat information about their health and well-being a lot at enrolment. For both groups, a small increase was observed in CRs who felt that they had to repeat this information at the end of the follow-up period.

Table 27: Assessment of eCCIS

	Intervention group		Comparator group		P-value	Total	
	N	%	N	%		N	%
When it comes to information about your health and well-being, do you feel that you have to repeat this information a lot when talking to different people treating and caring for you?							
At enrolment							
No, I usually have to give such information only once	205	46.8%	275	53.6%	0.111	480	50.5%
I sometimes have to repeat information	174	39.7%	166	32.4%		340	35.8%
I have to repeat information quite frequently	47	10.7%	55	10.7%		102	10.7%
Yes, I have to keep repeating such	12	2.7%	17	3.3%		29	3.0%
At end of evaluation period							
No, I usually have to give such information only once	168	41.8%	157	50.6%	0.004	325	45.6%
I sometimes have to repeat information	171	42.5%	96	31.0%		267	37.5%
I have to repeat information quite frequently	47	11.7%	50	16.1%		97	13.6%
Yes, I have to keep repeating such	16	4.0%	7	2.3%		23	3.2%

Overall, the answers given regarding the client satisfaction from the care recipients receiving the new integrated care service showed that the majority of the population had positive experiences and were satisfied with the new treatment (**Error! Not a valid bookmark self-reference.**).

In the IC group, more than 65% of CRs answered that the new service had increased their emotional wellbeing (65.6%), and that the new service had increased their ability to get along with their health condition in day-to-day life (67.7%). Half of the IC recipients answered that the new service had decreased their anxiety about their health condition (53.6%), and had decreased how lonely they felt (52.1%). Around 40% of CRs thought that the new service had increased the relationship with their family carer (43.3%), and 50% thought that the new service had improved the relationship with the professional carers looking after them. Around 82% of CRs indicated that they were satisfied with the new service, and that it was worth the effort involved in using it, taking everything into account. Lastly, more than 70% of the IC group said that they would like to continue using the new service in the future (73.5%).

Table 28: eCCIS results (integrated care group ONLY)

	Integrated care group	
	N	%
To what extent, if any, has the new service affected your emotional wellbeing? (eccis2_3) 65.6%		
It has increased my emotional wellbeing a lot	62	27.8%
It has increased my emotional wellbeing a little	84	37.7%
It has not affected my emotional wellbeing	76	34.1%
It has decreased my emotional wellbeing a little	1	0.4%
It has decreased my emotional wellbeing a lot	0	0.0%
To what extent, if any, has the new service affected your ability to get along with your health condition in day-to-day life? (eccis2_4) 67.7%		
It has increased my ability a lot	56	24.9%
It has increased my ability a little	96	42.7%
It has not affected my ability	73	32.4%
It has decreased my ability a little	0	0.0%
It has decreased my ability a lot	0	0.0%

	Integrated care group	
	N	%
To what extent, if any, has the new service affected your anxiety about your health condition? (eccis2_5) 53.6%		
It has decreased my anxiety about my health a lot	55	24.6%
It has decreased my anxiety about my health a little	65	29.0%
It has had no impact on my anxiety about my health	94	42.0%
It has increased my anxiety about my health a little	10	4.5%
It has increased my anxiety about my health a lot	0	0.0%
To what extent, if any, has the new service affected how lonely you feel? (eccis2_6) 52.1%		
It has decreased how lonely I fell a lot	37	17.2%
It has decreased how lonely I fell a little	75	34.9%
It has not affected how lonely I fell	100	46.5%
It has increased how lonely I fell a little	2	0.9%
It has increased how lonely I fell a lot	1	0.5%
To what extent, if any, has the new service affected your relationship with your family carer? (eccis2_7) 43.3%		
It has improved our relationship a lot	32	15.2%
It has improved our relationship a little	59	28.1%
It has not affected our relationship	117	55.7%
It has made our relationship a little worse	2	1.0%
It has made our relationship a lot worse	0	0.0%
To what extent, if any, has the new service affected your relationship with the professional carers looking after you? (eccis2_8) 50%		
It has improved our relationship a lot	34	15.9%
It has improved our relationship a little	73	34.1%
It has not affected our relationship	105	49.1%
It has made our relationship a little worse	2	0.9%
It has made our relationship a lot worse	0	0.0%
Overall, taking everything into account, how satisfied are you with the new service? (eccis3_1) 82.4%		
Very satisfied	83	35.8%
Fairly satisfied	108	46.6%
Neither satisfied nor dissatisfied	40	17.2%
Fairly dissatisfied	1	0.4%
Very dissatisfied	0	0.0%
Again, taking everything into account, is the new service worth the effort involved in using it? (eccis3_2) 83.1%		
Yes very much so	82	35.3%
Yes mostly	111	47.8%
Neither worth it nor not worth it	36	15.5%
No mostly not	2	0.9%
No certainly not	1	0.4%

	Integrated care group	
	N	%
Would you want to continue using the new service in the future? (eccis3_3) 73.5%		
Definitely yes	87	37.8%
Probably yes	82	35.7%
I am not yet decided	37	16.1%
Probably not	19	8.3%
Certainly not	5	2.2%

5.4.5 Discussion of findings

As part of the evaluation of CRs' experience with ICT supported integrated care service, we narratively assessed the answers from selected questions of the PIRU questionnaire on user experience of integrated care and the eCare Client Impact Survey (eCCIS). Overall, CRs from both care groups seemed very satisfied with the information and care that they were receiving. At the beginning of the project, more than 75% of CRs (both IC and UC group) thought that health and social care staff were informing them of what was going to happen next, around 85% thought that the different people treating and caring for them worked well together to give the them the best possible care and support, and only around 14% thought that they had to repeat information about their health and well-being a lot, when talking to different care givers. A small improvement was observed at the end of the follow-up period for both groups. For the eCCIS questions only assessed for CRs receiving integrated care, the majority described having positive experiences and were satisfied with the new treatment.

In the context of BeyondSilos, the measures of the PIRU and the eCCIS questionnaire were intended as additional information to help shed light on the user experience of integrated care performance. We hypothesised that the new service would have a beneficial effect on the service users' experience which would be reflected by a higher percentage of positive answers among the care recipients receiving integrated care. However, the answers showed very similar and positive responses in both care groups. Satisfaction surveys highlight that older people often tend to evaluate care more positively than younger people, which may be because older people's expectations of care are lower than those of younger adults[43]. A systematic review of older people's experiences in acute care settings[43] showed that the quality of technical care is often taken for granted by older patients, and good or bad experiences were described more often in terms of relational aspects of care. In the majority of the sites, it was the same professionals caring for both care groups, which might explain the similar answers between groups. In some of the sites, the new service consisted of increased data being available to health & social care professionals, so the service was not visible to CRs, which might also explain the similar result. CRs in most of the sites were very old and frail people, who were already receiving highly intensive and technological supported care. This may have meant that the benefit of any additional care initiative was overlooked. Some sites also mentioned that the positive answers in the two groups at both enrolment and end of follow-up might indicate a wish to receive or continue receiving what is considered the superior treatment among CRs.

Lastly, the MAST model emphasises the importance of using scientifically validated measurement tools when evaluating ICT solutions. In the case of "user experience" of integrated care, the best tool identified was the PIRU questionnaire. However, due to the diversity in the new integrated service implemented in the sites, it did not make sense to apply the full PIRU in all sites. It is not possible to say whether a difference in care experience would have been observed if we had assessed the whole PIRU

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[43] Bridges J, Flatley M, Meyer J. Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. International Journal of Nursing Studies:2010,47:89-107.

questionnaire. However, the sites discussed that a proper tool / questionnaire for assessing CRs' experience with ICT supported integrated care was missing, and should be developed for further projects, preferable in a European setting.

5.5 Individual care recipient experiences

As part of the process evaluation planned alongside the outcome evaluation, all sites were asked to examine CRs' experiences with the BeyondSilos treatment. The aim was to gain an understanding of CRs acceptance of the new treatment, including any possible barriers and facilitators in delivering integrated care with support from ICT. A case study approach was applied. The integrated care process was studied by means of semi-structured interviews. Two rounds of interviews were implemented. The first round of interviews was held 2- 3 months after receiving integrated care, and the second round was held at the end of the BeyondSilos follow-up period. In each round of interviews, a minimum of three CRs from each site were selected for the process evaluation. It was recommended to select CRs representing differences in terms of gender, age, co-morbidity, social needs and the like.

Interviews were conducted by local BeyondSilos staff, and followed a semi-structured interview-guide (see Appendix C). Local adjustments in terms of adding themes or questions were allowed; the guide was perceived as a minimum template for data collection. The interviews had to be conducted in a way that encouraged discussions and elaborations rather than yes/no answers. CRs were informed that they would remain anonymous in the communication of the findings. The interviews were estimated to last 45 – 60 minutes each. Reporting of interviews with CRs has been included as an English summary for each pilot site in the various site evaluation reports (Annexes 1 - 7).

5.5.1 Narrative summary of interviews

Out of the seven sites, five sites performed both rounds of interviews. One pilot site (Northern Ireland) decided not to perform interviews with CRs since the new treatment consisted of increased data being available to health & social care professionals, so the service was not visible to CRs. Another pilot site (Amadora) only performed interviews at the end of the trial period due to delays in starting the service.

From the beginning of the BeyondSilos project, the overall attitude among CRs towards the care has been very positive. They have a better care experience and feel safer with a whole team of professionals from different disciplines follow up their care plan. Some feel that they have gained more control of their own care, feel more responsible for their own health, and have a better understanding of their condition. In one site where vital sign monitoring equipment was implemented at home, the CR expressed content with the opportunity to have their vital signs monitored by professionals on a daily basis, since they generally felt concerned about their health. Other CRs have emphasised the social aspect of the project, and the importance of having someone to talk to and share how they feel, and receive consultation in case of a problem.

Some general, technical problems have occurred in most sites, where some of the CRs or informal carers find it complicated to work with computers, tablets or smartphones due to lack the technological familiarity and health literacy needed to make use of the devices. Still, a majority have expressed that the advantages of the new service outweigh the required extra effort.

The new expanded role of the CR in the care setting has highlighted some care management issues. Although CRs are content with the daily monitoring and the self-care routines, they perceive it as something extra on top of their usual care; they do not wish to substitute the human interaction they have with care professionals.

5.6 Key lessons learned

- A positive change in functional capability (both activity of daily living and instrumental activity of daily living) was negligible in the IC group. This suggest that the anticipated benefit from integrated care, in terms of assisting the care recipients in coping with their daily life activities have not materialised in the deployment sites.
- Acting on the believe that the new ICT supported integrated care service could make the care recipients feel safer, better taken care of and more in control of their own condition, we hypothesised that the service would have a beneficial effect on the psychological wellbeing of CRs, which would be reflected by a positive change in the GDS score for the CRs receiving IC. However, no positive change in the depression symptoms could be associated with the new integrated service.
- CRs receiving integrated care as well as those receiving usual care reported a very high satisfaction with the service provided; it was therefore not possible to show additional improvements in the integrated care group.
- Consistently, all CRs interviewed regarding their perspective of the new care reported that the care had a positive impact on their condition or care (e.g. feel safer, more in control of their own care, feel more responsible for their own health, and have a better understanding of their condition).
- The ICT solution has to be a complementary tool and not stand alone / replacement. Avoid the risk that patients rely on the ICT without any physical contact.

6 Domain 5: Economic aspects

A summary of the economic evaluation has been produced in cooperation between empirica and the sites. For a full version of the economic evaluation please see deliverable D7.6 Deployment plans for BeyondSilos Pathways for details of the economic aspects of the BeyondSilos integrated care services.

6.1 Summary

The assessment of the economic aspects of the BeyondSilos services was part of the socio-economic impact assessment which is reported in deliverable D7.6 “Deployment Plans for BeyondSilos Pathways and Integration Infrastructure”.

Putting into place ICT-supported integrated health and social care services means that a variety of stakeholders tend to be affected by changes to their working process, and often to their economic performance. In most settings, healthcare and social care are separately organised, delivered and recorded by organisations and their staff, who are separately funded, managed, and regulated. Further to this, in some countries third sector organisations are increasingly becoming involved in elderly care. Against this background, the socio-economic assessment was carried out in such way as to enable those parties implementing integrated care to make strategic decisions during the development and early operation of the new ICT-enabled BeyondSilos service model. The overall aim was to support the various regional stake holders in making the new integrated service:

- viable: working successfully;
- sustainable: maintaining a positive ratio of costs and benefits; and
- scalable: working for the widest possible range of patients.

A methodological approach and toolkit was adopted which is called ASSIST - Assessment and evaluation tools for e-service deployment in health, care and ageing. It enables pursuing a multi-stakeholder assessment, founded on cost-benefit analysis. In particular, when it comes to joined-up service delivery requiring collaboration across different organisations, this approach generally stands out from other assessment frameworks in that it:

- helps to identify and address stakeholders that lose through the implementation of a new service model when compared with previous practices, and who may thus become “veto players” when it comes to further pilot service mainstreaming / up-scaling;
- allows monitoring of the actual and prospective service development over time;
- includes non-financial factors that in many cases have a major impact on the behaviour of a stakeholder.

6.2 Key findings

A socio-economic impact assessment was performed for each site in relation to the specific BeyondSilos model implemented there. The number and types of the individual stakeholders involved in the service, and thus the analysis, varies considerably across sites.

Generally, the outcomes of the socio-economic impact assessment suggest that a positive overall socio-economic return model can be established for the majority of sites, albeit with varying rates of return.

However, a sustainable business model is not self-evident for each of the different stakeholders involved in the delivery of BeyondSilos services, at least not at every site under the assumption of unchanged framework conditions. Under the current service model, costs and benefits are not equally distributed across the individual stakeholders involved in service provision, meaning that benefit shifts may represent a hurdle for economically sustainable operation of the BeyondSilos model at some sites. Whenever such a change is to the disadvantage of a stakeholder, that one is likely to become a veto player that will reduce the overall utility and performance of the service, especially if that stakeholder holds a powerful role. To avoid veto players, it may become necessary to find additional (financial) incentives for stakeholders who are experiencing costs but no or not enough immediate benefits from the service. Another option would be to lower costs for the stakeholder group that is likely to become a veto player, e.g. by lowering current equipment cost, or the introduction of cost-sharing models.

Reaching_break-even takes longer than expected / desired, at least for some stakeholder groups. Services often take a comparatively long time to arrive at break-even. A counter measure can be to think about quick wins for stakeholders affected by delayed benefits and high and early costs.

From the perspective of the patients involved in the joined-up service delivery model implemented in the sites, a positive socio-economic return is expected to emerge over the assessment period. A closer look at the monetised benefits and costs reveals that the negative impacts of the new service model mainly concern additional time required to be spent by the patients in using the new system and services. Main benefit items for the patients are in most sites convenience due to less time spent on interacting with care professionals.

7 Domain 6: Organisational aspects

7.1 Introduction

All deployment sites were asked to assess the organisational aspects of the BeyondSilos services under three headings:

- **Structure**: Deployment sites described changes in communication and outlined important service integration aspects of the deployment within their site (facilitators and barriers). See section 7.2.
- **Process**: As well as the workflow and care pathways, sites prepared a table illustrating changes in work procedures from usual to new integrated care. See section 7.3. Furthermore, the concept of a matrix to identify the impact of introducing BeyondSilos services was introduced. Sites evaluated the interactions within and between six main care actors, interdependent on each other, who build up the care network. See section 7.4.
- **Professionals' perspectives:** Sites gained individual feedback and perspectives of different professionals through interviews. See section 7.5.

Details of these three aspects are reported in each of the Annexes for the seven deployment sites, Annexes 1 - 7. The sections below provide an outline of the approach, and a summary of the results.

7.2 Structure

The description of the structural outcomes is related to introducing ICT supported integrated care. Below, the effect of changes in communication is described, together with a description of service integration aspects, i.e. the barriers and facilitators associated with implementation of the ICT service in relation to providing integrated care.

7.2.1 Communication

Information regarding changes in communication after the implementation of ICT supported integrated care have been gathered through interviews with care professionals and through information collected from log-files describing the use (average number of log-ins and messages sent) of the ICT solution among the different professions involved in the delivery of ICT supported integrated care (when possible).

New ways of communicating both within and between the organisations involved have emerged with the introduction of the new BeyondSilos service. Electronic care summary plans available to both healthcare and social care providers have provided better coordination, faster decision making, and an increased empathy between disciplines, according to the interviews performed with the professionals (for more details see section 7.5). The use of ICT solutions has also helped to increase the professional’s awareness of the condition of the care recipients, and improved the communication and the relationship between care givers and care recipients and relatives.

Each site has completed a table with numbers from log-files describing the use of the ICT solution among the different professions involved in the delivery of ICT supported integrated care. Table 29 below is the template that the sites could use, adjusted to their own setting as necessary. However, many sites could not obtain this information due to the technical setup of local systems; e.g. some systems only registered when a change in the healthcare record was made, and not each time a professional accessed the system. Also, if the new BS system was integrated into an existing care system, the sites could not differentiate between a login related to the new BS service or a login related to usual care. In Annexes 1-7, each site has provided a table describing the use of ICT service by different professions, or they have provided an explanation as to why it was not possible to collect this information.

Table 29: Use of ICT service by different professions - template

Professions		Access		Messages	
		Average no. of		Average no. of messages sent to	
		Log-ins	Users per week	Health sector	Social sector
Hospital staff		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
GP		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Home nurse		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Social worker		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Volunteers	**Total**	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
	Family	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
	Church	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
	Other	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)

7.2.2 Service integration aspects (facilitators and barriers)

Each deployment site completed a table showing barriers and facilitators identified regarding technical, organisational, administrative and economic findings. The table compares findings at the beginning of the implementation of the BeyondSilos service and at the end of the evaluation period. Table 30 below shows the template in which data was collected.

Table 30: Overview of facilitators and barriers experienced at the beginning and end of implementing ICT in relation to integrated care - template

	Beginning of implementation		8 months after implementation	
	Facilitators	Barriers	Facilitators	Barriers
Technical				
Organisational				
Administrative				
Economic				

The facilitators and barriers identified by the sites at the beginning and end of implementing ICT in relation to integrated care were as follow:

Technical

Most sites indicated that the ICT systems are easy to use for the care givers, and also highlighted the benefits of good ICT support. However, the sites also indicated that:

- the systems are not always easy for the elderly people to use (buttons and icons appear too small);
- wifi-connections fail and devices lose Bluetooth link with tablet/PC; and
- they have experienced problems with:
  - data transfer;
  - log in accounts;
  - system failures; and
  - learning curves for ICT tools.

At the end of the trial period, fewer technical problems were reported. It was also stated that training of the users in the ICT devices has improved the situation. On the other hand, one site reports that care recipients used the help desk support when they felt lonely and needed someone to talk to.

Organisational

Most sites reported that they have experienced great support and engagement from the partners involved in the project, though one site found it difficult to get commitment from GP practices to participate, and another site missed the involvement of other care providers such as elderly associations, community associations, NGOs, etc. One site also raised the problem of convincing policy makers to deploy the BeyondSilos service at full scale, even though the new service is very well accepted among staff and care recipients.

Several sites reported that it seemed difficult for the professionals to set aside working time to engage in the project, and therefore they had to fulfil tasks related to the project in their leisure time, which effected the quality of the work. Also, changing the work routine for clinical staff caused some difficulties. By using and trusting the BeyondSilos service, they could avoid a lot of visits since they are now able to electronically track the care recipients' conditions. However, as part of the old routine, they still felt they needed to check up on the care recipients in person.

Administrative

It seems that the new horizontal integration of care has helped establish clear roles and given closer contact between professionals and project partners, and a shorter and quicker communication. However, for some the lack of support from the administrative departments has been a limiting factor. Further, the administrative workload to prepare deliverables for the project is considerable.

Economic

Most sites indicated that it has been very positive that a fixed budget was given to prepare the work and implementation process. However, there seems to be a reduction in the budget which has influenced the quality of the equipment that could be bought, and made it difficult to overcome unexpected work tasks related to technical errors. One site stated that bad planning prior to investment of the project budget has been a limiting factor. Another site described that the care recipients have been so content with the service that some of them are willing to pay in order to continue using it; however, due to a fully tax financed healthcare system, a co-payment is not possible.

7.3 Process

The findings on the processes related to the implementation of ICT supported integrated care were derived from several sources:

- The many contributions and deliverables or slides produced by the sites in which they illustrated, step by step, new advances in knowledge and practices for delivering new integrated care interventions, accordingly to the original scopes of the BeyondSilos project.
- The many meetings and teleconferences in which sites reported the advances in their work.
- Finally, from the results obtained by the use of some new original methods and tools aimed to specifically describe changes in the level (degree, entity) of integration between actors (integration matrix) during the course of the project.

7.3.1 Care pathways and workflow

Two types of ICT supported integrated care pathways were identified during the BeyondSilos project: short-term care following hospital discharge (up to eight weeks), and long-term care (longer follow-up period, at least six months), as needed by the care recipient.

The type of care interventions and pathways were described, and also graphically illustrated, in a number of deliverables:

- D1.1 Requirements for BeyondSilos Pathways and Integration Infrastructure.
- D1.2 Pilot level Pathways and Integration Infrastructure.
- D2.1 Organisational & Service Process Models.
- D3.1 Pilot level Service Specification.
- D3.2 Service Specification.
- D4.1 prototype test report.
- D4.2 Prototype system.

The entry points into both BeyondSilos pathways varied according to individual service users and deployment regions. However, most often the entry point was at the hospital or in community services (out-of-hospital services, usually at GP practices, but also social services). Individual care recipients could, for instance, be referred to the BeyondSilos service by health or social care professionals, already caring for them in other contexts, who had identified a need for more or a different type of assistance. Depending on the “business” model intended to be adopted for mainstreaming purposes, direct subscription to the BeyondSilos services by older people and/or their family was also an option in some sites. It could be a relative or the care recipient themselves that made the decision to ask for the BeyondSilos service because they were no longer able to handle the situation themselves with the present assistance and care. Examples of the latter can, for instance, be found in countries where non-medical telecare schemes (e.g. social alarms, home security sensing) are usually not provided as a public service under the auspices of the municipality or regional government.

Both health and social care providers were engaged to enrol CRs into the project. Social care providers were particularly participating in the enrolment of CRs in the sites of Kinzigtal, Amadora and Sofia. The tasks and roles were divided between the relevant care providers, depending on the type of pathway (long term or short term).

7.3.2 Changes in work procedure

Table 31 below summarises how work procedures have changed in each of the sites after introducing ICT supported integrated care.

Table 31: Changes in work procedures

Usual care	Integrated care
Northern Ireland	
Tele monitoring readings only visible to referrers via RTNI system.	Available via quick link from NIECR.
eNISAT assessment only available to a few.	Management plan details available to all via NIECR.
Care Summaries are paper based; accurate at time of completion.	Care Summary available to all in NIECR; changes reflected in real time.

Usual care	Integrated care
Kinzigtal	
Wound management description.	Description and photo of wound uploaded directly in CGM net.
Medication plan on printed paper before starting patient visits.	Updated medication plan available at patient's home via tablet.
Treatment documentation on paper.	Electronic documentation.
Communication between professionals via telephone or telefax.	CGM net as an information platform by uploading relevant information.
Lack of information leads to inappropriate decision or delayed decisions.	Faster decision making for professional based on social care information.
Patient feels insecure because of differing information from social care and GP.	Better coordination and consistent information improves feeling of safety for patient.
Valencia	
Telemedicine + Primary care (CMCP).	Telemedicine+ PC + social provider + ICT care platform.
Planned calls every three weeks (clinical perspective). Unplanned calls attended during working hours (8-15h).	Planned calls every two weeks (social and clinical perspective). Unplanned calls covered 24/7.
Patient social evaluation previous inclusion in CMCP.	Patient social evaluation previous inclusion and during planned calls. Planned visits to patient home (social environment evaluation).
Physiological measurement when patient receives / goes GP visits.	Physiological measurement sent by patient every week through a PC tablet.
Disease educational intervention during inclusion in CMCP.	Continuous disease educational intervention (in person during inclusion and through PC tablet on demand).
Transition of care from STC to LTC focused in clinical care.	Transition of care has both social and clinical care perspectives.
Campania	
Paper work.	Digital record.
Care paths not controlled.	Care paths well defined.
No control on costs.	Costs monitored.
No control on outcomes.	Reports on intermediate and final outcomes.
Low coordination in services.	Increased coordination.
Telemonitoring not available.	50 patients are on telemonitoring.
Limited evaluation scale.	Extended number of scales for patient assessment.
Amadora	
Social care (hygiene & alimentation).	Social & health care.
Tele-assistance.	Tele-assistance & telemonitoring.
Lack of structured training to formal / informal carers.	Structured training to formal / informal carers.

Usual care	Integrated care
Lack of ICT components / tools.	Online Platform (PAD) with telemonitoring & tele-assistance integration; b-Learning tool.
More people institutionalised due to lack of services / conditions at home.	Enhancing the possibility to continue living@home.
Badalona	
Third sector care providers outside of the formal provision of care.	Inclusion of the third sector as an available resource from every setting.
Use of telemonitoring solutions not extended.	Inclusion of the telemonitoring solutions as an available service.
Yearly evaluation.	Continuous evaluation.
Sofia	
User seeks medical care (routine examination of blood pressure).	Daily real time monitoring & control of user's medical condition.
Monitoring of user's chronic condition is fixed by law - GP / specialist / hospital.	Integrated (individual care) plan according to individual needs.
User has a separate health record and a separate social record.	Access by health and social care team to user's records.
No access to summary user's integrated record by health and social professionals.	Co-operation of professionals.
Unnecessary medical visits.	Timely access to care & advice according user's needs.
	Decreased risk of incidents / User feels more confident.

7.3.3 Staff and training

The types of staff and care givers involved in providing BeyondSilos services were, among others, nurses, doctors, physical therapists, social workers, psychologists, community nurses and family members. These staff received training to use the ICT platforms and telemedicine devices, and had the chance to work with the software during training sessions. Table 32 shows an overview of the number and different types of staff and care givers involved in providing the BeyondSilos services for each pilot site.

Table 32: The types of staff/care givers involved in providing of BeyondSilos services

Staff	Number	Detailed user type
Sofia		
Healthcare professionals	6	3 GPs 3 medical specialists
Social care professionals	3	Social workers
Informal carers; volunteer support	30	Family members, neighbours, friends
Northern Ireland		
Social care professionals	All with access to NIECR	HSC Trust Social Workers
Informal carers; volunteer support	0	At the present, informal carers or volunteers are not included

Staff	Number	Detailed user type
Kinzigtal		
Healthcare providers (GP practices)	4	GP
Social care providers	2	Ambulatory nursing service
Informal carers; volunteer support	0	Are not involved in new service. For the near future, no involvement is planned
Valencia		
Healthcare providers (GP practices)	<15	4 CMN 1 Supervisor Hospital and Primary Care staff
Social care providers	5	2 coordinator group 3 Tele assistance SW
Informal carers; volunteer support	<50	Patient relatives or Personal caregivers
Campania		
Healthcare professionals	102	7 specialists 70 GPs 25 nurses
Social care professionals	5	Social workers of the City Councils
Informal carers; volunteer support	97	97 family / informal caregivers
Amadora		
Healthcare providers	10	4 GPs 2 Nurses (1 Chief-Nurse) 2 Psychologists 2 Physiotherapists
Social care providers	41	5 Social Workers 36 Family Assistants
Informal carers; volunteer support	127	115 Relatives 12 Volunteers
Badalona		
Healthcare professionals	20	1 specialist 7 GPs 8 nurses 4 physiotherapists
Social care professionals	36	8 social workers 28 family workers
Informal carers; volunteer support	237	223 informal carers 14 volunteer support

7.4 Integration level

It is important to assess the level of integration and levels of performances of services as part of the processes related to the implementation of ICT supported integrated care.

One of the challenges in the seven deployment sites was to improve integration and integrated care, and to verify the support of ICT solutions in reaching this goal. Sites were engaged in a double commitment. First, major efforts were made to achieve better interactions, cooperation and collaboration between all actors involved in care delivery, at professional, managerial and institutional level. Great attention was also devoted to assure motivated participation and involvement of CRs and their relatives, in both planning and providing care. In addition, further efforts were necessary to use new informatics tools and technological devices to facilitate information exchange, faster communication, and better quality of home care services.

These challenges are as diverse as the sites themselves, in terms of different social, economic and political contexts. The organisational impact of the project actions is influenced by the very different characteristics of the population in the seven deployment sites, and the local cultures, traditions and habits of both care recipients and staff. The usual care starting point is also relevant for the outcome, as it includes the different baseline levels of integration between care actors (from none to already significant).

Detailed findings and the experiences of each of the seven deployment sites are described in Annexes 1 - 7.

The sections below provide an outline of the approach, and a summary of the results.

7.4.1 Methodology

In the literature, no strong evidence has been found that there is a positive association / correlation between levels of integration and levels of performances of services; that is, the greater the integration, the better the outcomes of care services. This may be due to the difficulty of measuring the degree of integration. Nevertheless, we have been acting on the hypothesis that this link exists, based on experiences in the field. Therefore the organisation was aimed to improve the level / extent of integration between care actors. Thus we have been looking for evidences or clues / signs indicating how integration and/or integrated care has changed (possibly improved) throughout the project interventions.

7.4.1.1 Usual care vs New care Matrix

In an attempt to describe the level of integration between sectors or/and actors involved in the care pathways, a shared pragmatic approach has been adopted to describe the reality (actual status) at start and the progression / variation of integration that occurred throughout the project. Each site has produced a table, called the “Usual care v New care Matrix”, reporting a self-assessment of the interactions and integration within and between actors.

Table 33 shows the template of the Usual care vs New care Matrix which the sites completed. Interactions between all actors, particularly within and between health and social sectors, had to be described for both usual care and new care, with the aim to show where major changes occurred from the beginning of the project up to the end of the evaluation period. The scope was to capture possible additional benefits in the “new” integrated care. The assessment was made by one professional in each site, who was deeply involved in the care practices, and had precise knowledge of the functioning of all services and their impact / acceptance by care recipients / families. She/he was responsible to provide a comprehensive overview of the local scenario.

The main care actors involved in care practices (care network) grouped in the matrix are as follow:

- **Health services:** these are the services belonging to the Local Health Authority or any agency formally entitled to organise / deliver healthcare to the resident population; the staff include doctors, nurses, therapists, etc.

- **Social services:** these are the services that are usually provided by municipalities or other similar public institutions (with some few exceptions) which have the mission to provide social support in various forms: direct services to the person, financial support, housing, etc.
- **Third Sector:** this includes all “aggregated forms” of delivery by non-public organisations, such as associations of volunteers, association of active citizenships, non-governmental-organisations (NGOs), etc., and any other non-institutional entity that might cooperate / collaborate in providing home services on the basis of formal or informal agreements / commitments with the public sector. In this framework, it is suggested to consider cooperatives formally providing complementary services as belonging to “other providers” (next).
- **Other providers:** these are organisations (private, profit or no-profit) other than those listed above who are engaged in the delivery of (home) care services; they can act as prevalent or complementary care agencies / providers with their own staff (care practitioners).
- **Person - care recipient:** they are fully entitled to be included in the series of “care actors” to emphasise that the person (care recipient / patient / other) plays an active role in the care programme (empowerment). Thus, they are “main actors” and cornerstones in the personalised care plan, principal protagonists of the care network.
- **Family – entourage:** as above, they are also fully entitled to be included in the list of “care actors”, since (mostly) family caregivers in general (including personal private assistants) play an active role in the care programme.

Table 33: Usual care v New care Matrix - template

	Health services	Social services	Third sector	Other providers	Person - care recipient	Family – entourage
Health services						
Usual care						
New care						
Social services						
Usual care						
New care						
Third sector						
Usual Care						
New care						
Other providers						
Usual care						
New care						
Person- care recipient						
Usual care						
New care						
Family –entourage						
Usual care						
New care						

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 gradation of interaction between sectors is followed by a short description by the site.

- None (No): No interaction between sectors / actors (including spontaneous or informal 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 workflows 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 items). A short description can be used.
- Unchanged (u): This only applies when the level of integration remained unchanged, irrespective of the starting point (has remained unchanged because of, for example, lack of time, no strategy-commitment, good starting value, etc.).
- NA: not applicable.

7.4.1.2 Integration Index Matrix

The "Integration Index Matrix" is a further development of the Usual care vs New care Matrix described above. It represents an attempt to quantify the type and extension of the integration within and between the care actors involved in integrated care during the project. The Integration Index Matrix has been developed by HIM during the BeyondSilos project, and has already been used with promising results in the SmartCare project.

The aim of the Integration Index Matrix is to describe in a pragmatic, visual and summary way if/how the level of integration between and within the services and the persons providing care has changed over the project lifespan in each deployment site. It helps to answer the unsolved simple question (for a complex problem): "What, where and how are the changes visible in the level (type, degree, direction, extent …) of integration in your local BeyondSilos deployment site, within and between all groups of care actors?".

The main care actors involved in care practices are grouped in the matrix; the gradation of interaction are the same in the Integrated Index Matrix as in the Usual care vs New care Matrix described above.

Information for the Integration Index Matrix was gathered and analysed through the two steps described below.

- **Step 1:** A 6x6 matrix was prepared in an excel file; the cells show mutual viewpoints of interactions (integration) within each actor / service, and between actors delivering care: a score is assigned in every cell accordingly to an ad-hoc scale; the levels are defined as follows: None, Low, Medium, High integration (as above). After the mid-term evaluation, a further category was added: Full integration, see below). Two other items were also available: Unchanged, and Not applicable.
- **Step 2:** The matrix from Step 1 was circulated to the deployment sites. To facilitate the completion of the integration index matrix, one-to-one instructions sheets were also distributed, then it was explained during a meeting; finally, individual teleconferences with the deployment sites were organised in which the matrix was discussed face-to-face between the medical coordinator and

each site representative. Then it was experimented and re-evaluated at local level, and finally updated and approved.

After mid-term evaluation (Sofia meeting), the scoring system for this scope was re-evaluated, and a new scale was agreed as follows:

- **None** ("no" in matrix): there are no interactions / joint care practices between other partners, neither in a formal nor in an informal manner; fragmentation (silos logic) is dominant. It implies that services operate independently from one another, and have no information about the other services; there is no communication, cooperation, or collaboration with other care actors.
- **Low** ("L" in matrix): interactions and integration between actors are perceived as at low level, but total fragmentation is avoided (as above). FACTS: Joint care practices occur only on a spontaneous or informal basis. There are no formal agreements in place between actors / sectors. Services are aware of other programmes / services, but rarely share information relevant for care; they communicate more on an informal than formal basis, with low level of cooperation and collaboration. There is a low frequency of contacts, meetings, joint actions, with almost no access to common data base, etc. (tangible-demonstrable events). Very low use of ICT is employed.
- **Medium** ("M" in matrix): interactions between actors are perceived as quite good. FACTS: they occur in routine practice more in a spontaneous (although at a higher degree than in "low" score), than in a planned manner. Joint care practices can occur on a formal basis, and some formal agreements / rules are in place. Services are aware of other programmes / services delivered by others, and quite frequently share information. There is a medium level of cooperation and collaboration, with a significant frequency of contacts, meetings, joint actions, access to common data base, etc. (tangible-demonstrable events). ICT facilities and instruments are quite diffuse and applied to enable better integration within and between care sectors, primarily in order to easily share information and data relevant to care.
- **High** ("H" in matrix): interactions between actors are perceived as good. FACTS: many formal agreements and guidelines used in routine practices are in place. Clear workflow between actors is defined; ICT solutions (not only to share data / information) are positively integrated, and are part of the work routine, at least in health and social services. Services are fully aware of other programmes / services, and routinely share relevant information; they communicate on a formal basis, with high level of cooperation and collaboration, with high frequency: daily / weekly occasions of contacts, meetings, joint actions, access to common data base.
- **Full**: ("F" in matrix): full integration occurs when all criteria and goals of the category "High" are present and resources from different sectors are pooled on the basis of formal agreements and ICT based record of care plus automatic transfer of data / information occur routinely. New organisations / comprehensive services are created. Constant and continuous cooperation and collaboration are a "natural" characteristic of daily work; joint care practices, developed with a fluent communication and information sharing, characterise the organisation. On the whole, ICT facilities (different types of tools) are used with the scope to add benefits for the care organisation (for care practitioners) and for the delivery of integrated care interventions in favour of the care recipients.
- **Unchanged** ("U" in matrix): This only applies when the level of integration has remained unchanged over time, irrespective of the starting point level (e.g. because of lack of time, of interest / willingness; of ad hoc strategy-commitment; because a good level has already been achieved; etc.). In the absence of the previous category "added value", it is recommended to use this category only when the status has definitely remained equal vs baseline status.
- **Not applicable** ("N/A" in matrix): use this option when in the local context, for any reason, there are no opportunities / occasions / circumstances to have reciprocity between actors (e.g. primarily

because one service is not active, or it is absent, or does not play a role in the integrated care network, for instance, absence of other providers or third sector in the specific local context).

Only at mid-term and end evaluation, another option was possible: “added value”. This may be applied when an improvement vs baseline was perceived by the evaluator, even if no perfect adherence to the criteria for an upgrading was evident.

As described, the criteria for each score were defined and refined more on the basis of the observations collected from all the sites, rather than from literature. Their value for in-field practice is thus greater and more original.

7.4.2 Result: Usual care vs New care Matrix

Table 34 summarises the main results across the sites. It reports only the most evident advantages generated by the introduction of new integrated care, as ascertained by professionals of the health and social services in the seven sites.

The specific information for each site (Usual care vs New care Matrix) is reported in the individual site annexes, Annexes 1 - 7.

Table 34: Cross-site summary of Usual care vs New Care Matrices

	Health services	Social services	Person- care recipient	Family –entourage
Health services				
New integrated care	Health services are a part of an integrated care plan. The telemonitoring tool allows the limited homecare health services to better monitor the status of the patient. All professionals can view the same information. Continuous follow up of health status.	Social and health services are co-ordinated via a common platform and according to an integrated care plan. Coordinated delivery of care. Better information quality based on data exchange and access to central electronic patient record. All professionals can view the same information. Social and health services are co-ordinated via a common platform and according to an integrated care plan.	The CR is an active part of his/her treatment and care. The CR can rely on constant health and social surveillance. It is now possible to make a self-assessment using ICT tools. Better information quality and maybe more time for CR based on information input from social care services via common electronic health record. Self-management through telemedicine + ICT tools, and social care follow-up though a social care provider.	The family can rely on constant health and social surveillance for their relatives. Support for patient management through telemedicine + ICT tools. Better information quality based on input from social care services, especially when family is involved in care processes. Accurate follow up / control of care recipients through e-Health assistance, and integration of care (social and health).

	Health services	Social services	Person- care recipient	Family –entourage
Social services				
New integrated care	Social and health services are co-ordinated via a common platform and according to an integrated care plan which leads to better information quality. Common evaluation; coordinated delivery of care. All professionals can view the same information. A new social provider who takes care of patients for evaluation and follow-up in social care.	Different social services are integrated as a part of an integrated care plan. 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. All professionals can view the same information. Continuous social support by visits and phone calls. Social services could be provided by regional government in some cases, and hired as a private company in others. Exchange clinical information; diary of primary care or hospital visits improves coordination and patient's social care.	The CR can rely on constant health and social surveillance and is actively involved in the planning and provision of social services. Patients receive assistance according to integrated plan + ICT. Better information quality and more time for CR. Tele-assistance social follow up for all CRs.	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. Support for relatives in assisting patients. Better information quality to family members based on information input from healthcare such as medication plan via common electronic health record.

In summary, these descriptions, which depict an “average” opinion drawn from several assessments coming from all sites, highlight that the main advantages and improvements of the new ICT enabled integrated care are in the possibility for health and social operators to join efforts and activities, primarily by sharing and facilitated information / data exchange. It derives an improvement of the perceived quality and timing of their care delivery, reaching better personalisation. It seems that the participation and involvement of both the care recipients and the family / care givers have been enhanced; on average, they appreciated the technologies for telemonitoring health and environmental conditions, so that this may improve the sense of security and well-being in remaining at home, very often alone, despite life difficulties.

7.4.3 Results: Integration index Matrix

The following table and figure summarise the general results observed in the seven deployment sites of the project. The results of the site level Integration index Matrixes are reported in the individual site annexes, Annexes 1 - 7.

Table 35 shows the total baseline, mid and final score values (absolute number of observations) ranking integration level.

Table 35: Integration Index Matrix: summary of the seven sites

TOTAL 7 SITES	Start	Mid	Final
NO	20	17	17
Low	88	60	60
Medium	56	34	34
Added value		8	10
High	40	62	60
High + Added value		10	10
Full		13	13

On the whole, the self-assessment has generated scores that indicate a general improvement in the level of integration. "Low" scores decreased from 88 (48%) at the start to 60 (32%) at the end. “Medium” scores dropped from 56 (27%) to 34 (18%), whereas “High” values increased from a baseline level of 40 cases (19%) to 60 at the end (33%). In eight cases at mid-term, the evaluators have indicated a progress in the degree of “medium” integration between care actors (“Added value”), without changes at subsequent step. In addition, 10 “High” baseline scores gained further success (“High+Added”). Finally, in 13 cases a “Full” score was attributed by the evaluators since the degree of integration between health and social actors or between institutional services and the care recipients / families reached the top level, according to the criteria / requirements.

Figure 9 and Figure 10 illustrate graphically the values of the previous table. In the first graph, the absolute numbers are shown, and in the second graph, numbers are expressed as a percentage.

From the graphs, it is clear that a shift of the values from the low to the high rank occurred, indicating that positive changes were recorded in the global interactions between all care actors involved in the project care interventions.

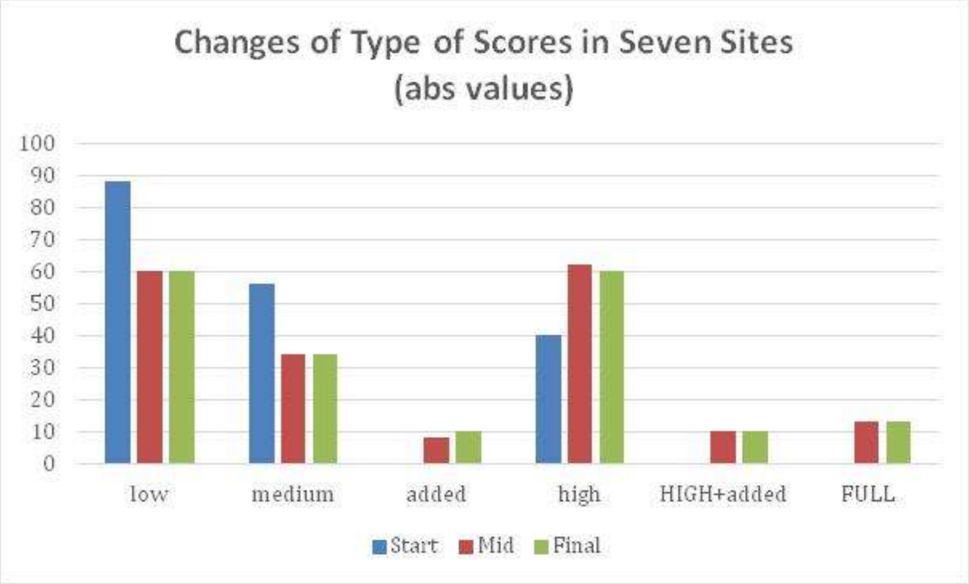

Figure 9: Total number of observations of each type of score in the seven sites

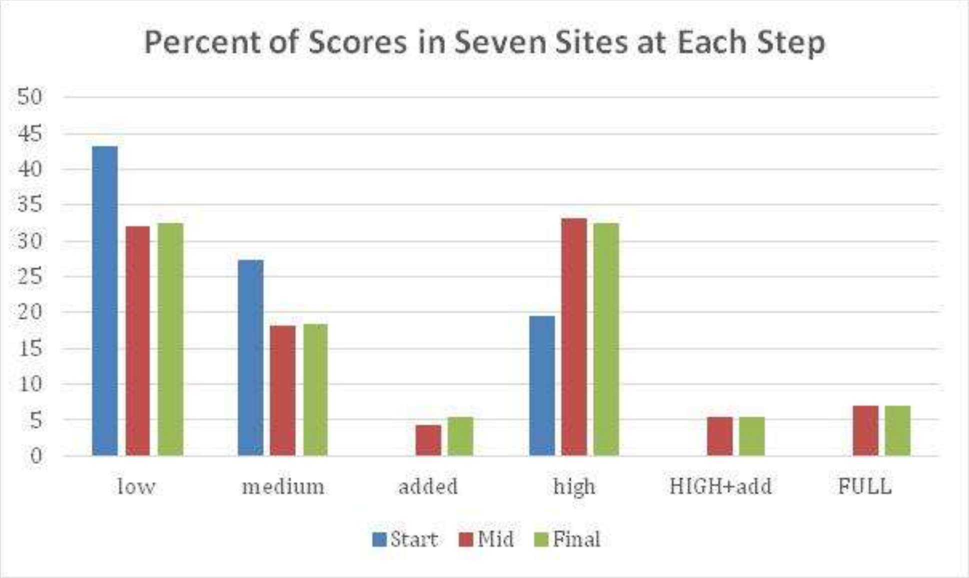

Figure 10: The percent of observations of each type of score in the seven sites

7.5 Professionals' perspectives

As part of the process evaluation, all sites examined the professionals' experience with the implementation of ICT-supported integrated care into their daily work routines. The aim was to gain an understanding of their acceptance of the new treatment, including any possible barriers and facilitators in delivering integrated care with support from ICT. The interview guide for professionals is presented in Appendix D.

It was recommended to select professionals from all the different occupations and sectors actively involved in the ICT supported integrated care (e.g. nurses, hospital doctors, home nurses, social workers and GPs), hence ensuring the possibility of studying the new service from the perspective of the different actors.

Deployment sites reported the outcomes of two rounds of interviews with the local care professionals using the service. Below is a summary of the interviews and some important views extracted from the interviews.

Out of the seven sites, five performed both rounds of interviews. Due to delays in starting the new services, two sites only had time to perform one round of interviews. The findings from the interviews for each pilot site can be found in Annexes 1 – 7.

7.5.1 Summary of results: Professionals' perspectives

Overall, the health and social care professionals are satisfied with the BeyondSilos services. The new services have improved the coordination and information flow between social and health care providers, which have resulted in better management of the care recipients. In addition, the time spent overseeing CRs has been optimised so that the professionals can monitor more CRs while giving them better care. However, it is also emphasised that the ICT supported services should be complementary treatment, and cannot stand alone without any physical contact by professionals. The medical professionals seems more keen and experienced in the use of ICT, while the social care professional more often advocate the importance of personal contact. Some social workers interviewed indicated feeling inexperienced in using the ICT tools, which for some led to a greater work load. One site reported that nurses working closely with the care recipients felt that although the ICT tool is a good concept, the CR needs more technical training in order to trust the tools and use them correctly.

Some views representative of all professionals are provided below.

Advantages pointed out by professionals:

- The new workflows between social care workers and health care professionals enhance and boost the process of planning, communication, monitoring and supervision, at the same time that the level of responsibility in taking decisions increases.
- The collaboration between silos has led to faster decision taking, an increase of empathy between disciplines (social and health), and an increased sense of security and confidence regarding the operation of teams in the field.
- Professionals see as a benefit that they are saving time and money for patients; it also saves their own time, as they can manage their workload better; the time required for face-to-face contacts with the user is reduced.
- Better integrated care implies improving information and data sharing: a benefit of monitoring the condition of patients with chronic diseases is the daily information about the vital signs (6 out of 7 sites applied telemonitoring); daily contact with them is the opportunity for contact also with relatives who can provide additional status information for a patient when necessary.
- It allows better management because it can improve the coordination between social and health care. In addition, it can optimise the time spent with the care recipients, because they can look after more patients in the same time.
- The ICT solutions have increased their awareness of the CRs' conditions, and improved relationship with patients and relatives.
- The monitoring can improve the co-responsibility between professionals and users, because the users' role changes with it.
- It reduces the level of anxiety that patients experience when left alone to deal with their condition, as happens in usual care.
- The ICT solution increases the empowerment and awareness of patients regarding their conditions.

- The use of technology by older people enables them to make more contacts, thus avoiding social exclusion.

Pitfalls pointed out by professionals:

- There is a risk if patients rely on the ICT without any physical contact. The ICT solution has to be a complementary treatment and not stand alone / replacement.
- Technical issues were highlighted. When technical problems arise, there is a need for fast and adequately technical support to avoid problems. Speed of tablet / internets and cultural issues are preventing the implementation and proper use of the service.
- Although the tools provide updated relevant information to help make the best decisions regarding the diagnosis and treatment of patients, the time it took for them to learn to use the tools was also emphasised.
- If more professionals from the social care institutions and in the nursing home would use the new technology, there would be more synergy effects.
- The benefits the GP expected from the ICT solution were not fulfilled properly, because too few patients were involved in the service, and more data should been exchanged and uploaded by social care. GPs still believe that this is the right tool to optimise communication between professionals.
- For social care professionals, the ICT tools are new to them. Even though they are very well informed about how the ICT systems work, they feel inexperienced in using them.
- The medical professionals are keener on the use of ICT, while the social care professional advocate the importance of personal contact.
- The study is time consuming, and it is difficult to get locums to cover work.
- A longer trial is needed to show the full benefits in terms of time saved, etc.
- The innovation requires an acceptance from the patient's family that is not always found among clients. Some resistance from the elderly people to use technology is underlined. Nevertheless, all staff believe that it is a substantial improvement in daily practice that is welcomed.
- There is a need for patient’s technological education improvement to achieve success with the new integrated care model, because the use of technology has been a great barrier for elderly patients.

7.6 General findings observed in sites

- All sites shared the experience to activate or improve a new service based on personalised care programme with multidimensional-multiprofessional needs assessment of the person.
- All social and health professionals in all sites acknowledged the advantages of joint care interventions to meet the needs of multiproblematic care recipients (“complex patients”). Coordination, interaction and integration between professionals and services have been looked for during the whole project: all sites declared that this process ended in an improved system of human factors engaged in field practices.
- In many sites, a renewed participation of the informal care “sector” was experienced. This is important in view of the construction of new care networks in the territories aimed to achieve a well-balanced equilibrium between formal and informal care (with a shift towards the latter, in order to make more sustainable and more effective the prospective welfare systems).

- Special attention was devoted by all care teams to improve empowerment and participation of care recipients and their families / care givers. This is now a diffuse attitude in all sites, and might be considered as an important success.
- Staffs have well taken on board the fact that all the above mentioned elements represent the correct and only basis to develop real effective integration and, as a consequence, well based integrated care.
- Sites benefited from the use of ICT facilities, even if in different ways, with quantity / quality of ICT products. In general, two lines were opened or reinforced:
  - the adoption of a personal electronic record (EPR), with both health and social issues; and
  - telemonitoring of vital and/or environmental parameters.

  A unanimous consensus exists between sites that the EPR now is an indispensable tool for a modern integrated care system.
- Social services of many sites are now closer and more prone to use the EPR and ICT facilities (e.g. environmental sensors).
- All services in all sites are now more able to work on an outcomes-based perspective, rather than on process-evaluation.
- Respect of equity and necessity to acquire the consent of patients were also two diffuse topics that improved.

7.7 Key lessons learned

- Integrated care is a process and not the goal; therefore the efforts for its improvement should be constant. Reaching the “tangible” effects of better integration requires more time than expected (planned). No one single parameter may indicate “the success or the benefit” of integrated care.
- Integration is based mainly on human factors; coordination, interactions and integration largely depend on the will of the professionals to abolish barriers and build alliances with the common goal to deliver high-quality services, to serve in a more efficacious way the care recipient (and her/his family entourage), who must be involved in and participate in the care programme.
- The staff that better accepted the innovation in organisation and adoption of ICT facilities were those who were better motivated at the beginning and well supported during the project.
- The social sector should receive more attention and support than the health sector to move in the direction of integrated care. In general, the social sector seems to be less mature than the health sector in introducing changes in service organisation and the use of new technologies.
- Integration is expressed at professional, organisational and institutional level. In the first and second, the responsibilities go to care practitioners; in the last, a unique responsibility is taken by policy makers and top level managers. When the three levels really cooperate and are perfectly linked, an integrated system can grow. Without a high and clear commitment by the top level of administration, it is impossible to reach the top level of integration and full integrated care.
- The electronic personal record speeds communication, facilitate exchange of information of care relevance (especially in the health sector), and the preparation of common agenda. These opportunities are essential for case / care managers. When chronic diseases are present, such as cardiac failure, respiratory insufficiency, diabetes, which all share the necessity to be followed-up by means of objective clinical measurements (blood pressure, weight, etc.), telemonitoring of vital parameters may facilitate good control of the clinical conditions at home, the empowerment of patients, updates of therapies by doctors, with even more connections / synergies between GPs and specialists.

- New services aimed to reach high quality integrated care take great benefit from the use of a personal electronic record, which contains both health and social data/information. However, the ICT solution has to be a complementary tool and not a standalone / replacement. Avoid the risk that patients rely on the ICT without any physical contact.
- The selection of elderly people as candidate for the use of ICT facilities may be more difficult than expected, and, when they accept, adequate time to teach them must be planned, with proper time also provided for home reinforcements during the first few months. This suggests that, despite some exceptions, the long-term adoption of ICT enabled integrated care, rather short-term care programmes, may produce better results.

8 Domain 7: Social, ethical and legal aspects

8.1 Overview

The domain includes topics that identify the ethical, legal and socio-cultural aspects of the BeyondSilos project. The information has been collected and reported by key project members for each deployment site, e.g. clinical leads, project managers, service managers. They in turn have collected the information within their local project and specialist teams.

The issues are categorised as follows:

- Ethical issues:
  - Overall questions: Does the application challenge religious, cultural or moral beliefs?
  - Potential ethical problems, e.g. giving responsibility to the care recipients.
  - Autonomy: Is the care recipient’s autonomy challenged or increased?
  - Justice.
  - Beneficence / non maleficence.
- Legal issues:
  - Clinical accreditation.
  - Information governance.
  - Professional liability.
  - Care recipient control.
- Social issues:
  - Changes in the care recipient’s role in major life areas (e.g. social life, working life).
  - Care recipients’ relatives and others’ understanding of the technology.
  - Societal, political context and changes. Will the service influence the general model for the delivery of healthcare service if deployed?
  - Changes in responsibility. Are the care recipients and/or relatives capable of handling their responsibility?
  - Gender issues. Has the service any consequences on the position of gender?

8.2 Ethics and Data Protection Framework

BeyondSilos entailed two issues that were sensitive from an ethical and legal perspective, and therefore crucial for the project. Firstly, including older European citizens in a new form of service delivery demanded the use of ethical standards to be sustained throughout the project. Secondly, intensive integration of services and hence sharing of healthcare and social care related data of older European citizens had to comply with local, national and European regulations regarding e.g. data protection and privacy. To safeguard these two crucial issues, a framework was drawn up to cover both aspects, covering issues such as consent forms, and submissions to the ethics committees at each site, etc. This document, D8.2 BeyondSilos Ethics and Data Protection Framework, provided fundamental guidance on these two crucial issues, and served throughout the duration of the BeyondSilos Project.

8.3 Ethical issues

8.3.1 Ethical scrutiny

The fundamental question about ethical issues is whether the work of the deployment sites has been subject to ethical scrutiny at any point.

Only three of the seven sites (Badalona, Valencia and Amadora) reported that they were required to apply for approval for the BeyondSilos project from their local ethics committees. All three sites received this approval. Valencia reported that some clarifications were asked by the ethical committee regarding the Inform Consent form for care recipients after the social care provided (ATENZIA) was included in the study as a stakeholder. The protocol was thereafter approved, which means that the protocol fulfilled all legal and ethical aspects regarding privacy, management, and patient's right about information governance. Amadora and Badalona did not report on that any further clarifications were needed.

The remaining four sites all reported that there was no requirement to obtain ethical approval for the project. In case of N. Ireland, the project did not have to be registered at the Research Ethics Committee since the project involved the integration of existing systems into an existing electronic care record. Kinzigtal reported that only when research in humans is planned, the ethical commission must be involved based on the Helsinki Declaration. Campania stated that since the BeyondSilos built on the existing integrated Home Care offer, no new ethical approval was requested.

Due to the local set-ups of the BeyondSilos project, and to the fact that no human experimenting was performed, only three of the seven pilot sites were required to obtain ethical approval for the project. There is no evidence about rejection of the protocols. Therefore, we conclude that the protocols and generally the local projects comprised terms and conditions which ensured the application of the principles of bioethics.

8.3.2 Principles of bioethics

The evaluation of the ethical aspects of the BeyondSilos project is based on the four core principles of bioethics[44]: autonomy, equity - justice, beneficence and non-maleficence.

8.3.2.1 The principle of autonomy

The principle of autonomy relates primarily to the ability of the care recipient to decide whether they want to participate or not in a medical research or healthcare programme. The autonomy must relate to both thought / intention and final act. An important condition of a valid consent is previously informing the potential participant. The information should be full, clear and appropriate for each patient.

In case of BeyondSilos project, and particularly in the case of the deployment sites, where ICT equipment was used by the care recipients, the informing should not be limited to the information required for any medical practice or any clinical trial. In these cases, additional information should be provided regarding how to use the devices, as well as on the obligations that the care recipient would be under due to their participation (e.g. regular measurements, communications with medical and other staff, etc.) and the potential risks of their participation.

According to the local deployment evaluations (Annexes 1-7), all sites were very careful to give detailed information to participants about the project, both written and oral, and also the opportunity to express their queries or doubts throughout the duration of the project. The procedure for informing about the BeyondSilos programme and collecting informed consent at a site level is summarised:

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[44] Beauchamp and Childress - 2008

- Amadora reported that the Operational Team of the project performed home visits where the Informed Consent form was read to the care recipients to make sure they had understood before giving their approval.
- Badalona stated that several information meetings were held with users & relatives, and that they were able to contact Badalona by telephone if they had any concerns or needed clarifications.
- Campania collected informed consent to handle personal data and enrol in the project which had to be signed by the care recipients.
- In Kinzigtal, social care providers informed the care recipients about the pilot intervention face to face; care recipients had the opportunity to ask questions regarding the intervention. After oral consent, care recipient had to sign a written document to record their consent. At any time, the care recipient was allowed to withdraw their participation.
- N. Ireland presented patient information leaflets to care recipients prior to seeking consent to take part in evaluation. The patient consent was collected orally by the GP. No written consent was required.
- In Sofia a care recipient information pack was created; nurses were trained to deliver oral guidance with the written information, and care recipients’ consent was recorded in writing. A two week cool-off period was introduced to allow care recipients to withdraw after considering the written guidance provided by nurses.
- In Valencia care recipients were orally informed about the project by the case management nurse, once they accepted to participate. A document with study information and consent form was taken to the participant's home to be signed, and was stored in a locked filing cabinet in the telemedicine department.

Each person reacts differently to the use of technology. Therefore a risk may arise from participation due to the use of telemedicine and ICT solutions. Especially when the use of technology relates to healthcare, it is possible that CRs are affected psychologically, or they develop "interpersonal' relations with the equipment, positive or negative. Telemonitoring / teleconference / teleconsulting give CRs the opportunity to enjoy care, information and education whenever they need. So these methods contribute to the independence of CRs, the achievement of self-management of the disease, and strengthening self-reliance and autonomy. In such cases, the termination of the project may cause depression and anxiety to CRs.

In the process evaluation of the care recipients’ experience with the BeyondSilos service, several CRs from different sites expressed that they felt safer, more in control, and more responsible for their own health. However, there is no evidence about the information given to the CRs regarding how to cope with the termination of the project and the service.

As a conclusion, we acknowledge that the sites made a big effort to give the necessary information (written and orally) to care recipients and family members, who had the right to ask questions during the programme and to exit the programme whenever they wanted. It seems that the participants were sufficiently informed regarding the procedure and their obligations / rights, and that all their queries were answered properly. However, there is limited information regarding whether this included all necessary information, and if all this information was fully understood by the participants. Particularly, information regarding how the sites were planning to deal with elderly who suffered from mental or other diseases which affect the ability to comprehend was vague, especially since no sites reported excluding CRs who were not in a position to understand and sign the consent form. Furthermore, there was not enough evidence about how the sites informed CRs about the psychological impact of using ICT devices and the termination of their use.

8.3.2.2 The principle of equity – justice

The principle of equity – justice requires that healthcare must be fairly distributed and scarce resources allocated and competing needs, rights and obligations be fairly considered. Risks, burdens and benefits of new or experimental treatments must be distributed equally among all groups, regardless of sex, race, economic situation, residence, etc.

As far as the BeyondSilos project is concerned, justice relates mainly to issues of fairness with regard to equal access to the services provided.

In theory, the BeyondSilos treatment could be used on and benefit many different types of care recipients with health and social needs. However, for the BeyondSilos evaluation, CRs were selected on the basis of a set of eligibility criteria agreed on by all sites and set out in deliverable D6.1BeyondSilos Evaluation Protocol. This meant that only CRs complying with the inclusion and exclusion criteria set out in section **Error! Reference source not found.** had access to the services provided.

As far as the BeyondSilos project is concerned, justice relates mainly to issues of fairness with regard to equal access to the services provided. We do not have any details about the number of potential CRs who could have benefitted from the BeyondSilos service, but were excluded on the basis of these inclusion and exclusion criteria. Therefore, we only apply the principle of equity – justice on the potential group of care recipients according to the eligibility criteria.

In order to secure equal opportunities for the new service for all the care recipients who met the inclusion criteria, most sites randomly allocated CRs to either the new integrated care service or the usual service.

However, some local circumstances did not always allow for proper randomisation. For example in Northern Ireland, the care recipients were selected by GPs based on their knowledge of the patients' needs and the risks associated with their health and social situation. Though all participating GPs stated that they had allocated care recipients with similar characteristics to both intervention and control group, it cannot be ruled out that the new BeyondSilos treatment might have been allocated more often to certain types of care recipients, therefore preventing equal access to the service.

Amadora offered all care recipients the opportunity to use the services, and hence did not have a parallel comparator group receiving the usual treatment. Instead, all CRs enrolled in the project served as their own comparator at an earlier point in time. This was done in order to prevent injustice with regard to equal access to the services provided. In most, sites recruitment of CRs only took place after they had been signalled by GPs, nurses, or social workers, which means that only CRs with a known need could be enrolled and benefit from the service.

The participation in the project also depended on other factors, namely familiarity with technology. Although electronic devices in most cases were provided by the sites, CRs often had to meet the economic cost and needs of the project concerned with internet connection or telephone line.

Nevertheless, although we have no details about the number of potential CRs who were excluded because of lack of equipment or technical knowledge, we conclude that the principle of equity was not applied regarding all its fields and conditions. Although measures were taken in order to secure equal access to the services, and some of the necessary equipment was offered as part of the project, the economic, social and other inequalities did not allow the indiscriminate participation of all interested parties.

8.3.2.3 The principles of beneficence and non-maleficence

The principles of beneficence and non-maleficence (assessment of risk and benefit), involve the obligation to prevent and remove harms and to promote the good of a person by minimising possible harms and maximising possible benefits.

Concerning the project, the principles of beneficence and non-maleficence relate to data protection, privacy and confidentiality, improvement of quality of care, easier access to services, decrease of anxiety by providing the CR with a sense of security, and improvement of overall CR satisfaction about their care and use of ICT equipment.

Protection of data, privacy and confidentiality are linked with legal issues, so they are included in the following section.

It is generally accepted that the benefits and disadvantages must always be assessed in relation to each specific patient. For instance, for some the feeling of security, which may be a result of the programme, may outweigh the distress that may be caused because of being monitored / cared for by unknown third parties, while for others the use of technology may be perceived as physically obtrusive. In addition, how intrusive and interventionist is the existence of telemedicine equipment or the nurses / social workers in the home of the patient is a criterion for whether the specific service harms or benefits. The use of technological equipment may cause stress to patients because they are unsure about handling them, and worried about correctly measuring results. Finally, a disconnection from the platform used or the internet may cause anxiety and discomfort to the users.

In every case, the possible advantages and disadvantages should be assessed not only in relation to the CR, but also to the other residents of the house.

We should also not assume that the technology, aiming at helping the CR, is "good" for all. Therefore, beyond the measures taken by the sites in the interests of patients, the sites should also take into consideration the impact of the programme, not just before recruitment, but also during the programme.

Such detailed information about the impact of technology on the patients and their families is not recorded by the sites. The only relevant information is included in the interviews with the care recipients. According to them, several care recipients from different sites expressed that they felt safer, more in control and more responsible for their own health due to the new BS service. Nevertheless, it is not safe to make conclusions from such a small number of interviews.

Another ethical issue associated with the said principles is whether the participant patients were burdened by the non-continuation of the programme after the end of the project. The question which arises is whether the patient will be able to meet the needs of his/her illness in the traditional care and hospitalisation, or he/she will have lost completely the ability and willingness to go back to the previous situation. However, there is no evidence on this issue, except from some interviewees who expressed their wish for the programme to be continued, so the impact of the termination of the programme cannot be evaluated.

8.3.3 Normative codes

The pilot sites did not report about inadequate codes of practice or other relevant issues that had to be solved.

Valencia stated specifically that any new intervention that is evaluated in the department has to be approved by ethical committee in the framework of a clinical research study.

8.3.4 Overall questions

Finally, according to the deployment sites, there is no evidence about cultural, gender related, religious or moral beliefs to be challenged by the services provided.

8.4 Legal issues

All sites list the national applicable legislation about data protection, research, medical protection, healthcare acts, rights of patients, information system; some of them refer to European legislation.

The provided services in every site complied with the referenced legislation.

None of the sites referred to any need for changes in order to adapt the service to meet legislative requirements.

8.4.1 Professional liability

The existing mechanisms were sufficient for the service, as no site adopted specific measurements during the programme, because the professionals involved were no different to the ones for the usual care.

Northern Ireland stated that only established GP practices were involved.

In Amadora it was not an issue, given that all the staff involved already delivered services in other health facilities of SCMA.

8.4.2 Device accreditation / certification

None of the sites referred to any problems with certification of the devices or substitutions that had to be made. In most sites, only existing systems and devices were used which already conformed to all requirements.

As described in Domain 6 (organisational aspects). all sites reported that staff received training to use the ICT platforms and telemedicine devices, and had the chance to work with the software during training sessions.

8.4.3 Care recipient control

The issues about care recipients control are linked to ethical issues, so they are analysed above (ethical issues).

8.4.4 Information governance

One of the most important legal issues is information governance, which relates to collection, transfer, storage, access and processing of personal data. For the BeyondSilos project, interest in the right of privacy of data is increased because of the use of ICT, which concerns the ICT equipment and/or the connection / access of databases.

This particular issue links with ethical issues and some of the critical elements have been included in the section on ethical issues (consent and informed consent).

8.4.4.1 The security of transfer and storage of data

According to second year review recommendations, all sites signed a statement of compliance with national data protection laws. In most sites, care recipients were requested to sign both informed consent and authorisation for handling of personal data.

Table 36 shows an overview of the national data protection laws that were followed by the sites.

Northern Ireland stated that data collection for the evaluation was conducted within existing regional systems which operate within all relevant legislation and rules. Only the GP and other health and social care professionals dealing with the care recipient could access the system. Furthermore, all patients' data was anonymised by GP practices prior to sending for input to database.

Amadora sent a letter to the Ethical Committee for data protection and a letter signed by SCMA assuring the quality of the processes.

Badalona stated that their information systems were compliant with the legislations according to the security requirements and that all accesses are logged (login and data accessed).

Kinzigtal ensured that electronic patient record system fulfilled the requirements of German federal data protection act (BDSG), especially §4 (requirements for data use), §1 (self-determination of data, data secrecy) and §11. Employees are obligated to be educated in data protection requirements of BSDG.

Sofia stated that: firewalls required adjustment that had been made; access protocols were revised; care recipient access ensured (reference to new protocols). Furthermore, they provided a letter of compliance with the data protection security rules.

Valencia stated that HUPLAFE ethical committee approved the study protocol, which meant the protocol met all legal and ethical aspects regarding privacy, management and patient's right about information governance.

Table 36: Overview of national data protection laws followed by pilot sites

Country	Laws
Italy	Legislative Decree 196/2003 - Legislative Decree 196/2003
UK	Data Protection Act of 1998
Spain	Data Protection Law Organic Law 15/1999 Safety of medical information Law 41/2002 Royal Decree 994/199
Portugal	Law nº 67/98. DR 247/98 Série I-A 1998-10-26 – Law of data protection Law 43/ 2004 – Law of organisation and functioning of National Commission for Data Protection (CNPD)

Country	Laws
Germany	German federal Data Protection Act (BDSG) of 1990 For the end 2014, the Ministry of Health plans an e-health act to regulate the requirements for the use of electronic health card in Germany.
Bulgaria	Data Protection Act (2002): Art. 1(2) Health Act (2005): Art. 28b

8.4.4.2 The issue of data access

Northern Ireland stated that only the GP and other health and social care professionals dealing with the care recipient could access the system.

In Badalona, all care recipients have the right to ask for access logs, and to deny access to health information to professionals.

Sofia stated that the care recipient access was ensured.

In Valencia, ethical committee approval of the protocol ensured that the management and patient's right about information governance met all legal and ethical aspects regarding privacy.

According to the above, most of the sites were very interested in the protection of data, and for that reason they took several measures. However, the descriptions are missing some information regarding which procedures that were implemented.

Except for Badalona and Sofia, the other sites did not give specific information about the procedure of access to data for care recipients.

Finally, we mention that none of the sites refers to the right of care recipients to ask for the correction of their data during the project.

8.4.4.3 The issue of privacy

Northern Ireland stated that all patients' data was anonymised by GP practices prior to sending for input to database.

In Badalona, the privacy of data was secured by several measures. Documents on access and confidentiality assurance must be provided by all agents. Users have the right to ask for access logs, and to deny access to health information to professionals. Relatives and guardians must have a formal "Delegation of Access" form presented at the Badalona by the user.

Campania stated that in compliance with the terms and indications of Italian Law 196/2003, regulating the treatment of data of persons and other subjects, the processing and handling of personal data needs to be carried out respecting the rights, fundamental freedoms and dignity of natural persons, particularly with regard to privacy and personal identity. Each citizens needs to sign a consent to provide and handle personal data. The consent may be withdrawn at any time.

Kinzigtal stated the electronic patient record system met the requirements of German federal data protection act (BDSG), especially §4 (requirements for data use), §1 (self determination of data, data secrecy) and §11. There is an official contract between Gesundes Kinzigtal and service provider Compugroup for handling data in the network.

None of the pilot site referred to any legal issues that came up and had to be addressed.

8.5 Social issues

8.5.1 Changes in the care recipient's role in major life areas

As far as the changes in social life are concerned, the deployment sites gave the following information:

- Amadora reported that the service made the care recipients feel more confident and secure regarding their health.
- Campania reported that with the new service, the care recipients had more direct involvement in self-care and a greater sense of security / safety. Also, that there were more symmetrical relationships with professional stakeholders.
- Sofia reported that receiving the treatment at home on a regular timetable enabled the care recipients to go to hospital less often.
- Kinzigtal reported that the new service resulted in staying longer at home, and delayed admission to nursing homes.
- The new integrated care in Valencia aimed to improve CRs' knowledge and deal with self-management. They and their caregivers played an active role in their own care, measuring and sending data and receiving information, becoming more conscious about their health status. Most of the participant intervention group reported that they felt safer and better surveyed with all devices, and expressed their will to continue after BS evaluation.

Although not all sites gave specific information regarding the changes in social life, most of them have reported in the interviews with care recipients (Domain 4) that the CR were more actively involved in their care and health situation, and some of them reported that they felt more secure during the programme.

8.5.2 Care recipients' relatives and others

Only four sites reported on CRs' relatives' involvement.

- Amadora stated that when CRs received treatment at home, it enabled relatives to stay in the labour force and to stay more autonomous.
- Campania stated that the new integrate care enhanced the feeling of social support and security.
- Sofia indicated that the informal cares received support from a team of professionals.
- Valencia reported that many of CRs had very low ICT knowledge and needed help to deal with technology. Relatives often played a large part in the care since they had to assist with the measuring and sending data.

None of the sites reported any information regarding whether relatives felt more anxious during the project. However, none of them expressed negative comments about the project or the services.

8.5.3 Societal, political and context changes

Three of the sites report that the participation in the BeyondSilos project had helped them highlight integrated care at home.

- Amadora stated that BeyondSilos had put integrated care delivered at home on the map of the priorities of SCMA, and also in the priorities of Amadora Municipality in order to spread the model throughout all the council.

- Campania stated that the dissemination and communication work had stirred interest and awareness in integrated care.
- Sofia indicated that the project had helped make Integrated care a policy issue, furthering legal changes.

8.5.4 Changes in responsibilities

Except for the additional responsibilities of CRs and their relatives, most of the sites brought up the increased level of responsibility among professionals due to the introduction of integrated care.

- Northern Ireland stated that GPs felt that collaboration with CRs was improved; however, there was concern that access to information increased others' perceptions of what a GP should be responsible for.
- Amadora stated that the professionals accept the increased the level of responsibility if it is for a major cause such as integrated care and collaborative work.
- Campania replied that nurses and social workers have started taking on more active roles within domiciliary integrated pathways.
- Sofia stated that CRs assumed more responsibility for their treatment and care.
- Valencia specified that patients had learnt to be proactive. Despite feeling safer because the use of technology, many of them still leave responsibility for their health to professionals and caregivers.

8.5.5 Gender issues

There were no gender issues at any site.

8.6 Summary

8.6.1 Ethical issues

Due to the local set-ups of the BeyondSilos project and to the fact that no human experimenting was performed, only three of the seven sites (Badalona, Valencia and Amadora) were required to obtain ethical approval for the project. There is no evidence about rejection of the protocols.

The core principles of bioethics were applied in the local sites, even though the issue of justice was not addressed concerning some of its fields.

All sites were very careful to give detailed information to the participants about the project, written and orally, and also the opportunity to express their queries or doubts throughout the project. Most sites also stated that CRs also had the right to exit the programme at any time.

There was no evidence about the psychological impact of technology and the ending of the project on participants, or about cultural, religious or moral beliefs to be challenged by the services provided.

No other ethical issue was reported.

8.6.2 Legal issues

All sites complied with the applicable national and European legislation about data protection, research, medical protection, healthcare acts, rights of patients, and information system.

There was no need for changes as far as the professional accreditation and liability were concerned, because the professionals involved were no different to the ones for the usual care.

Deployment sites took all the necessary measurements for the protection of collection, transfer, storage, access and processing of personal data.

8.6.3 Social issues

Although not all sites gave specific information regarding changes in social life, most of them have reported in the interviews with care recipients (Domain 4) that CRs were more actively involved in their care and health situation, and some of them reported that they felt more secure during the programme.

None of the sites reported information regarding whether relatives felt more anxious during the project due to the larger role they often played in the care.

Except for the additional responsibilities of care recipients and their relatives, most of the sites brought up the increased level of responsibility among professionals due to the introduction of integrated care.

Three of the sites report that participation in the BeyondSilos project had help them highlight integrated care at home. But no sites reported specific societal, political or context changes during the project.

No gender issue was reported.

8.7 Key lessons learned

Briefly, seven main lessons drawn from the many direct experiences are listed:

1. In order for all fields of justice- equity principle to be applied, there should be more concern about the participation of care recipients who:
    - are not familiar with the technology;
    - do not have the economic ability to meet the needs of a project;
    - suffer from intellectual impairment;
2. ICT supported integrated care could be used for and benefit many different types of care recipients with health and social needs. Therefore it should be considered how the principle of equity – justice is affected by applying strict eligibility criteria as in the BeyondSilos project.
3. Care recipients feel safer, more in control and more responsible for their own health when participating in the project. More information regarding how to cope with the termination of the project and the service should be given.
4. Even though there was no professional liability issue during the project, we should note that no deployment site made any amendment regarding the ethical and professional rules of the professionals involved. Each group of professionals complied with its rules; this could cause conflicts and embroilment if a liability issue came up during the project.
5. The deployment sites seemed to be very experienced about the data protection issues (they took sufficient measures); however, they did not address the right of privacy of the care recipients and their relatives and carers when sharing sensitive information between sectors, which links with the ethical and legal issues.
6. The role of relatives and carers is very important for the implementation of such projects. Thus there should always be a provision for their duties during a project, and their reaction and burden because of it. Finally, in case that they have to participate actively, they should sign a relevant consent form. Moreover, each project should be evaluated from their perspective.
7. Care recipients are willing to accept the changes of the roles of the professionals involved in their healthcare, and they seem to feel safe and satisfied when they have the necessary attention and care.

9 Transferability

Transferability refers to the degree to which the findings from the BeyondSilos project can be transferred to other contexts. Transferability is very closely related to the term external validity, and answers the questions:

- Are the findings applicable to other contexts and situations?
- Can the findings be generalised?
- Can the findings be applied beyond the boundaries of the project and the deployment sites?

In other words, can we "transfer" the results of our project to another context?

In BeyondSilos, transferability includes topics that identify cross-border transferability, scalability and generalisability. The information has been collected and reported by key project members for each deployment site, e.g. clinical leads, project managers, service managers.

- **Cross-border:** Assesses whether the results be valid (or similar) in other countries as well.
- **Scalability:** Assesses whether the results will be valid (or similar) if the intervention is scaled to e.g. country-level.
- **Generalisability:** Assesses whether the results will be valid (or similar) if intervention is generalised to more care recipients e.g. with other conditions or severity of the present condition.

9.1 Transferability: Cross-border

The principle of collecting and sharing vital data by using ICT solutions and telemonitoring devices between sectors is universal, and the sites agree that this aspect of the BeyondSilos project is very much transferable across borders. Large parts of the components from BeyondSilos can be transferred to other settings, or duplicated by using local similar solutions. However, most of the local BeyondSilos services are embedded in national or regional healthcare systems whose structure and reimbursement system are not easily transferred between borders. Some important considerations brought forward by the local deployment sites include:

- Badalona: The financing aspect and governance are key facilitators towards the deployment of integrated care, and need to be taken into account in order to ensure cross-border transferability.
- Amadora: Our findings would be valid in any other country with similar challenges such as: elderly people living at home in a frail situation and dependent on social and health care services; with a high dependency on public and/or not for profit services; and with a lack of previous experience regarding ICT usage.
- Valencia: In order for our system to be transferable, it would require the installation of high level technology. However, in the last years a previous stage of BeyondSilos has been presented and very well received among healthcare organisations in Portugal, Italy and France.
- Sofia: Emphasises the importance of ensuring political support and willingness before introducing more effective integrated care, and highlights the role of innovative solutions at a reasonable price.
- Kinzigtal: Because of missing compatibility of the system with systems in other countries, transfer might lead to dysfunction. Before planning any implementation, the different components should be tested in a prototype scenario and an assessment should be made on how results would change if setting aspects were different.
- NI: The BeyondSilos pilot in Northern Ireland expanded on 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. We built on the Telemonitoring NI service and integrated it, thereby providing health and social care teams with common access to patient and client data. Interfacing the eNISAT with the ECR has enabled the transfer of information, including risk assessments, between professionals, and helps to facilitate a smoother journey for the service user along the care pathway. The technical process of integrating the two systems into the NIECR, which is an Orion system, is not replicable, as it is specific to the commercial systems involved. However, the principle of sharing the data is universal.

- Campania: At the moment, our service is mostly used in Salerno by patients with elevated needs, therefore consuming a high level of resources. In other settings, where the Integrated Home Care might be used for delivering prevention care, the result might be of larger impact, depending on the costs.

9.2 Transferability: Scalability

Applying the service to a larger population would hopefully imply lower costs. The savings that derive might cover the costs of home care, and implement a modern and more sustainable healthcare system. Some of the BeyondSilos sites are already scaling the service up to regional or national level. In Northern Ireland, all the systems involved are regional and available across Northern Ireland, and so could be made available to all users by simply raising awareness of the fact that the integration has happened, and highlighting the introduction of the Shared Care Summary. In Kinzigtal, scalability exists and the service use could be extended not only in the region of Hausach but also to the whole region of Kinzigtal; use is also possible in nursing homes and hospitals. In Portugal, integrated care at home in less than a year is a spread out practice, so it can be particularly interesting to scale this model to other territories given the fact that the majority of those have the same settings. In Valencia, the technology is completely scalable at regional level, because the main hospital and healthcare organisations in the public health system in Valencia Region share the same information systems. However, the platform has to be prepared to increase its capacity; this is currently limited to 5.000 users maximum. In Campania, the procedure could be used by the hospitals to implement early discharge. The savings that derive from early de-hospitalisation might cover the costs of home care, and implement a modern and more sustainable health care system. However, a larger number of patients necessarily implies smaller costs, otherwise the procedure cannot be sustainable.

9.3 Transferability: Generalisability

The current inclusion criteria for the BeyondSilos project have resulted in the selection of the oldest, most frail care recipients. Most of the sites have stated that the availability of more information for less ill care recipients may produce better results, as optimal clinical decision-making should lead to a reduction in exacerbations of conditions by early risk detection, and ultimately may help to slow down the progression of chronic conditions. The following considerations have been brought forward by the local deployment sites:

- Campania: Providing elevated intensity of care to those patients that are more ill is probably the less efficient business model. These patients have by definition an elevated risk of hospitalisation and events. The choice of intermediate levels of intensity of care, as well as the use of Home Care to deliver primary or secondary prevention, could result in a more efficient business model, with a better ratio between costs (which will be lower for lower intensity of care) and benefits (which will be higher, for the vitality of the events in these lower risk population). The drawback is the need to include a larger number of patients. But an appropriate choice of patients might help reduce the number of patients needed to be treated to observe an improvement.

- Amadora: The site implementation was focused on the eligibility criteria defined by the project, which means that if disease criteria changed, the type of services would also have to change accordingly to the type of disease. The main focus of Amadora site was on prevention more than on intervention. So, BeyondSilos constituted the trigger of a future portfolio of services that will be delivered soon regarding intervention.
- Badalona: The experience gained within the BeyondSilos project suggests that the inclusion criteria could be broadened when it comes to disease selection. The age range could also be better tailored by avoiding older patients (75+), and maybe including younger ones with chronic conditions (starting at 50 years).
- Kinzigtal: Service could be used for every single situation where medical and social data need to be exchanged.
- NI: The availability of more information to assist clinicians in making optimal decisions is not constrained to specific patient cohorts, so should benefit those with other diseases and other age groups. The current inclusion criteria have resulted in the selection of the oldest, most frail patients. Availability of more information for patients who are not so ill may produce better results, as optimal clinical decision-making should lead to a reduction in exacerbations of conditions, and ultimately may help to slow down the progression of chronic conditions.
- Sofia: More diseases can be included with no major changes to the business model. Broadening the scope of intervention might change the appropriate care pathways.
- Valencia: Results from BeyondSilos are very important inside our organisation, because, Health Department Valencia La Fe made a commitment in the last years to deploy integrated care services supported by ICT, leading to participation in BeyondSilos. Other initiatives are already being evaluated in our hospital. Through a national grant, a telemedicine service supported by Nomhad platform is deployed to follow up patients with inflammatory bowel disease in Hospital La Fe. Some other initiatives have been proposed regarding specific diseases or interventions (Diabetes Type II, or post-surgery rehabilitation) that could also benefit from BeyondSilos results.

9.4 Summary

- The principle of collecting and sharing vital data by using ICT solutions and telemonitoring devices between sectors is universal, and is very much transferable across-borders.
- Large parts of the components from the BeyondSilos can be transferred to other settings or duplicated by using regional / national similar solutions.
- Most of the local BeyondSilos services are embedded in national or regional healthcare systems with structures and reimbursement systems that are not easily transferred between borders.
- Applying the service to a larger population would hopefully imply smaller costs.
- The savings that derive might cover the costs of home care, and implement a modern and more sustainable healthcare system.
- Some of the BeyondSilos sites are already scaling the service up to regional or national level.
- The current inclusion criteria have resulted in the selection of the oldest, most frail care recipients.
- The availability of more information for less ill care recipients may produce better results, as optimal clinical decision-making could lead to a reduction in exacerbations of conditions by early risk detection, and ultimately may help to slow down the progression of chronic conditions.

10 Key findings and conclusions

10.1 Project setting:

- The overall aim of the BeyondSilos project was to optimise the care continuum for elderly care recipients with multiple co-morbidities and social needs by providing better integrated care (to overcome fragmentation between silos) with the support of ICT. It was hypothesised that the introduction of ICT supported integrated care would improve integrated care, and hence care recipients' perspectives, mainly emotional well-being, social needs and satisfaction, while at the same time reduce their need for hospital admission and contacts with health and social care providers.
- The evaluation of the project was based on a version of the seven domains in the MAST evaluation framework adapted to fit ICT supported integrated care. 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).
- This report addresses the European added value of the project by combining individual patient-level data from each site in order to identify common characteristics using valid statistical methodologies and other analysis methods. In order to overcome the multi-level diversity in the project, we have tried to identify possible common confounders, at patient as well as site level.
- Due to the diversity seen in the project, deployment site level evaluations are considered extremely important; the full reports are attached as annexes in this document; these are considered important elements of the project level evaluation.
- The number and complexity of components being implemented in the BeyondSilos project differ between sites; some regions integrated a few components such as electronic health and social records, while others also included triage systems, systems to help patient data management, decision support and scheduling, telecare communication, training platform, behaviour monitoring, vital sign monitoring, ambient monitoring, remote device administration, emergency communication, and personal data protection.
- A large focus has been given to training all end-users, both at the start of the service, and when needed thereafter, through workshops, training from key staff members, and implementation of helpdesks.

10.2 Results:

- Overall, 1,104 care recipients (CRs) were enrolled in the BeyondSilos project; 518 CRs in the intervention group received integrated care (IC), and 586 in the comparator group usual care (UC). More than half of the CRs were female, and 80% were aged 75 or more. 42% had a low level of education (less than primary school).
- Almost 80% of the population completed the full follow-up period.
- More CRs were lost to follow-up in the IC group than in the UC group. However, the IC group were also followed for a longer period than the UC group.
- ICT solutions have been demonstrated to be safe in regards to both technical safety and care related safety. There was no statistically significant difference in mortality between the care groups.
- By implementing the BeyondSilos services, all seven sites are now devoting more specific attention to improving home care services, placing them as a priority for the new organisation of innovative

valuable care settings for long-term conditions. This is particularly true for heart failure, but also for diabetes, COPD, stroke and fractures, especially when associated with social needs.

- The IC group and the UC group had very similar baseline characteristics. However, when comparing the baseline characteristics between the sites, some variations were observed in gender distribution, age, social support and primary diseases.
- Around 60% of CRs had received some kind of social support (most often logistic support such as meals, cleaning) at the beginning of the BeyondSilos project.
- Although the first admission to hospital occurred earlier for the IC group, unadjusted analyses suggested that their annual admission rate and annual length of hospital stay were significantly lower than for the UC group.
- The IC group had a lower readmission rate to hospital within 30 days even though they had a longer follow-up period.
- The regression analyses showed that a significantly lower number of unplanned hospital admissions were observed for the IC group. However, after adjustments for a number of possible confounders, this difference was no longer found to be statistically significant.
- No differences in total number of admissions to hospital, total number of days in hospital or total number of days of unplanned admissions in hospital were observed, which was also confirmed by the confounder adjusted regressions analyses.
- An increased annual number of contacts with health and social care professionals have been reported in the IC group. However, these findings have to be interpreted cautiously, because of a number of limitations, e.g. different numbers of CRs, different length of follow-up, small sample sizes, etc. The individual site level analyses showed a significant reduction in the annual contact rate for three of the sites. Fewer annual physical contacts were registered in the IC group than in the UC group, which corresponded with findings that contacts in the IC group were more often conducted by telephone or by home visits, and less often by physical meetings outside of the home residence compared to the UC group.
- The results of questionnaires on depression and social needs (measured by functional capability) did not show the expected success in the intervention group, probably due to insufficient quality of data and collection difficulties, but it might also be due to the large difference in dependency levels and depression scores observed at enrolment.
- CRs receiving both integrated care as well as usual care reported a very high satisfaction with the service provided; it was therefore not possible to show additional improvements in the integrated care group.
- Consistently, all care recipients interviewed regarding their perspective of the new care reported that the care had a positive impact on their condition or care; e.g. felt safer, more in control of their own care, felt more responsible for their own health, and had a better understanding of their condition.
- Care recipients are willing to accept changes in the roles of the professionals involved in their healthcare, and they seem to feel safe and satisfied when they have the necessary attention and care.
- There was no evidence about cultural, religious or moral beliefs to be challenged by the services provided. There were no gender issues in any site.
- All sites listed and complied with the national applicable legislation about data protection, research, medical protection, healthcare acts, rights of patients, information system; some of them referred to European legislation.

- ICT solutions have been demonstrated to facilitate and improve:
  - access to and sharing of data highly relevant for better care;
  - real time communication between all care actors and care recipients;
  - support for a more safe and comfortable life at home;
  - care recipients ability to make more contact with others, thus avoiding social exclusion;
  - collaboration between silos; this has led to faster decision making, an increase in empathy between disciplines (social and health), and an increased sense of security and confidence regarding the operation of teams in the field.
- The BeyondSilos project focused on care recipients who because of their advanced age and frail state were in an elevated need of care; some were already in intensive care before the start of the project. Given their advanced conditions at enrolment, it might be that any beneficial effect that ICT supported integrated care could have shown on the selected indicators were masked by the normal age-related deterioration associated with a population of frail older people. More research is therefore needed in order to identify proper measures of ICT supported integrated care in order to demonstrate the full advantage of the service and for the EC and European citizens to take full benefit of the results in this project.

10.3 Transferability

- The principle of collecting and sharing vital data by using ICT solutions and telemonitoring devices between sectors is universal, and is very much transferable across-borders.
- Large parts of the components from BeyondSilos can be transferred to other settings, or duplicated by using similar regional / national solutions. However, often the set-up of the local BeyondSilos services is embedded in national or regional healthcare systems with structures and reimbursement systems that are not easily transferred between borders.
- Applying the service to a larger population would hopefully imply lower costs per patient. The savings that derive might cover the costs of home care, and implement a modern and more sustainable healthcare system.
- Some of the BeyondSilos sites are already scaling the service up to regional or national level.

10.4 Challenges

- A number of challenges have been clearly acknowledged during the project and considered as the starting point for this evaluation. Most of these challenges are due to the fact that the project has been conducted in real life conditions, and had to deal with the major differences that exist in the way care is organised in different regions, and with very different starting situations between one region and another. These challenges includes:
  - Recruiting participants: Several sites reported difficulties in recruiting care recipients, especially for the IC group. The reasons for this were, among others, scepticism by both CRs and family members towards having or using tele health solutions in their homes. Some sites also reported that the defined inclusion criteria had a limiting effect in relation to reaching recruitment numbers.
  - Allocation of care recipients to care group: Prior to enrolling CRs in the BeyondSilos project, all sites had planned how to allocate CRs to either the integrated care group or the usual care group. However, most pilot sites experienced that due to difficulties in the recruitment process, a strict randomisation or matching process was not possible.
  - We have to acknowledge that our desire to collect as much and diverse data as possible with repeated measurements (start, mid, end) might has had a negative effect on the response rate

of the study population. Their high age and frail condition might have contributed to a reluctance to answer some questions, therefore introducing missing answers.

- Due to the above mentioned challenges it is recommended that in future projects more emphasis should be put into supporting and guiding sites in the recruitment phase, measurements, data collection, upload to central web database, and data analyses.

10.5 Factors for successful deployment

- Integration is based mainly on human factors; coordination, interactions and integration largely depend on the will of the professionals to abolish barriers and build alliances with the common scope to deliver high-quality services, and to serve in a more efficacious way the care recipient (and her/his family entourage, as possible), who must be involved and participate to the care programme.
- The staff that accepted the innovation in organisation and adoption of ICT facilities better were those who were better motivated at the start, and well supported during the project.
- Social sector should receive more attention and support than health sector to move in the direction of integrated care. In general, the social sector seems to be less mature than the health sector to introduce changes in service organisation and the use of new technologies.
- Integration is expressed at professional, organisational and institutional level. In the first and second, responsibilities go to care practitioners; in the last, a unique responsibility is taken by policy makers and top level managers. When the three levels really cooperate and are perfectly linked, an integrated system can grow. Without high clear commitments by top level of administration, it is impossible to reach top level of integration and full integrated care.
- New services aimed at reaching high quality integrated care benefit greatly from the use of a personal electronic record, which contains both health and social data/information. However, the ICT solution has to be a complementary tool and not stand alone / replacement. Avoid the risk that patients rely on the ICT without any physical contact.
- The electronic personal records speed communication, facilitate exchange of information of care relevance (especially in the health sector), and the preparation of common agenda. These opportunities are essential for case / care managers. When chronic diseases are present, such as cardiac failure, respiratory insufficiency, diabetes, which all share the necessity to be followed-up by means of objective clinical measurements (blood pressure, weight, etc.), telemonitoring of vital parameters may facilitate the good control of the clinical conditions at home, the empowerment of the patients, updates of therapies by doctors, with even better connections between GPs and specialists.
- The selection of elderly people candidate to the use of ICT facilities may be more difficult than expected and, when they accept, adequate time for teaching them must be planned, with proper time also provided for home reinforcements during the first few months. This suggests that, despite some exceptions, the long-term adoption of ICT enabled integrated care rather short-term care programmes may produce better results.

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Appendix A: Additional baseline and follow-up data

Table 37: New York Heart Association (NYHA) Functional Classification of patients with chronic heart failure at base line

	Intervention group		Comparator group		P-value	Total	
	N	%	N	%		N	%
NYHA I	79	33.6%	68	24.0%	0.003	147	28.4%
NYHA II	84	35.7%	94	33.2%		178	34.4%
NYHA III	61	26.0%	86	30.4%		147	28.4%
NYHA IV	11	4.7%	35	12.4%		46	8.9%

Table 38: New York Heart Association (NYHA) Functional Classification of patients with chronic heart failure at the end of follow-up

	Intervention group		Comparator group		P-value	Total	
	N	%	N	%		N	%
NYHA I	80	25.7%	75	19.5%	0.054	155	22.3%
NYHA II	79	25.4%	119	31.0%		198	28.5%
NYHA III	109	35.0%	120	31.3%		229	32.9%
NYHA IV	43	13.8%	70	18.2%		113	16.3%

Table 39: The National Institutes of Health Stroke Scale (NIHSS) of patients with stroke at the end of follow-up

	Intervention group		Comparator group		P-value	Total	
	N	%	N	%		N	%
No Stroke Symptoms	177	63.2%	251	72.5%	0.064	428	68.4%
Minor Stroke	41	14.6%	28	8.1%		69	11.0%
Moderate Stroke	26	9.3%	25	7.2%		51	8.1%
Moderate to Severe Stroke	15	5.4%	18	5.2%		33	5.3%
Severe Stroke	21	7.5%	24	6.9%		45	7.2%

Table 40: Social support at the end of follow-up

	Intervention group		Comparator Group		P-value	Total	
	N	%	N	%		N	%
Technical support such as "panic button", "GPS tracking" at enrolment	116	22.4%	106	18.1%	0.072	222	20.1%
Logistic support such as "meals", "cleaning", "laundry", "home fixing" at enrolment	355	68.5%	400	68.3%	0.922	755	68.4%
Personal support such as "family workers", "day care centres", "punctual accompaniment (to medical visits)", "company for risk exclusion avoidance" at enrolment	368	71.0%	371	63.3%	0.006	739	66.9%
Loan services support such as "wheel chairs", "crutches", "adapted bed" at enrolment	178	34.4%	184	31.4%	0.295	362	32.8%

Appendix B: Negative binomial regression analyses for hospital admissions

B.1 Total number of admission to hospital

Number of cases with valid hospitalisation_total	806
Number of cases with valid cases of all independent variables	794
Number of cases after removing outliers and multicollinearity	793

The following tables provide tests of the model as a whole (Omnibus Test). The likelihood ratio chi-square provides a test of the overall model comparing this model to a model without any predictors (a "null" model). We can see that our model is a significant improvement over such a model, as p-value < 0.05.

In the Tests of Model Effects table, we see that the predictors "primary_chf", "region_Badalona ", "region_Valencia" and "region_Amadora" are statistically significant.

Omnibus Test

Likelihood Ratio Chi-Square	df	Sig.
292.541	12	0.000

Tests of Model Effects

Source	Type III		
	Wald X^2	df	Sig.
(Intercept)	2.629	1	0.105
care_group	0.018	1	0.894
Gender	0.874	1	0.350
primary_chf	6.818	1	0.009
primarydia	0.150	1	0.699
region_NorthernIreland	1.058	1	0.304
region_Badalona	40.907	1	0.000
region_Valencia	24.107	1	0.000
region_Amadora	73.401	1	0.000
region_Kinzigtal	0.058	1	0.809
AGE	0.085	1	0.771
LFU	1.106	1	0.293
CCI	0.012	1	0.913

The table Parameter Estimates contains the negative binomial regression coefficients for each of the predictor variables along with their standard errors, Wald chi-square values, p-values and 95% confidence intervals for the coefficients.

Compared to patients who suffer from primary Congestive Heart Failure (primary_chf=1, our reference category), the expected log count for patients not suffering from primary Congestive Heart Failure in the long term decreases by 0.32. At the same way, compared to patients from Badalona (reference category), the expected log count for patients not deriving from Badalona decreases by 2.22. Compared to patients from Valencia (reference category), the expected log count for patients not deriving from Valencia decreases by 1.77. Moreover, compared to patients from Amadora (reference category), the expected log count for patients not deriving from Amadora decreases by 2.94. Finally, there isn't enough information to estimate the dispersion coefficient, (Negative binomial).

Compared to care recipients from Badalona (reference category), the expected log count for care recipients not deriving from Badalona decreases by 2.22. Compared to care recipients from Valencia (reference category), the expected log count for care recipients not deriving from Valencia decreases by 1.77. Moreover, compared to care recipients from Amadora (reference category), the expected log count for care recipients not deriving from Amadora decreases by 2.94

Their comparators outside of their region.

Parameter Estimates

			95% Wald CI		Hypothesis Test				95% Wald CI for Exp(B)	
Parameter	B	Std. Error	Lower	Upper	Wald X^2	df	Sig.	Exp(B)	Lower	Upper
Intercept	5.293	1.647	2.065	8.521	10.328	1	0.001	198.873	7.883	5016.940
[care_group=0]	0.018	0.139	-0.254	0.291	0.018	1	0.894	1.019	0.775	1.338
[care_group=1, intrvention]	0^a							1.000		
[gender=0]	0.104	0.111	-0.114	0.323	0.874	1	0.350	1.110	0.892	1.381
[gender=1] male	0^a							1.000		
[primary_chf=0]	-0.324	0.124	-0.567	-0.081	6.818	1	0.009	0.723	0.567	0.922
[primary_chf=1]	0^a							1.000		
[primarydia=0]	-0.055	0.141	-0.331	0.222	0.150	1	0.699	0.947	0.718	1.249
[primarydia=1]	0^a							1.000		
[region_NorthernIreland=0]	-0.478	0.464	-1.387	0.432	1.058	1	0.304	0.620	0.250	1.541
[region_NorthernIreland=1]	0^a							1.000		
[region_Badalona=0]	-2.221	0.347	-2.902	-1.540	40.907	1	0.000	0.109	0.055	0.214
[region_Badalona=1]	0^a							1.000		
[region_Valencia=0]	-1.770	0.360	-2.476	-1.063	24.107	1	0.000	0.170	0.084	0.345
[region_Valencia=1]	0^a							1.000		
[region_Amadora=0]	-2.936	0.343	-3.607	-2.264	73.401	1	0.000	0.053	0.027	0.104
[region_Amadora=1]	0^a							1.000		
[region_Kinzigtal=0]	0.125	0.518	-0.890	1.140	0.058	1	0.809	1.133	0.411	3.127
[region_Kinzigtal=1]	0^a							1.000		
AGE	0.002	0.008	-0.014	0.018	0.085	1	0.771	1.002	0.986	1.019
LFU	-0.001	0.001	-0.003	0.001	1.106	1	0.293	0.999	0.997	1.001
CCI	0.003	0.027	-0.050	0.056	0.012	1	0.913	1.003	0.951	1.058

The variables "region_Campania" and "region_Sofia" have not been included in the analysis due to multicollinearity.

The analysis was conducted after recoding the remaining variables as follows:

Variable	Coding
[care_group=0]	Comparator
[care_group=1]	intervention is the reference category
[gender=0]	Male
[gender=1]	female is the reference category
[primary_chf=0]	No

Variable	Coding
[primary_chf=1]	Yes: reference category
[primarydia=0]	No
[primarydia=1]	Yes: reference category
[region_NorthernIreland=0]	No
[region_NorthernIreland=1]	Yes: reference category and stands for Northern Ireland
[region_Badalona=0]	No
[region_Badalona=1]	Yes: reference category and stands for Badalona
[region_Valencia=0]	No
[region_Valencia=1]	Yes: reference category and stands for Valencia
[region_Amadora=0]	No
[region_Amadora=1]	Yes: reference category and stands for Amadora
[region_Kinzigtal=0]	No
[region_Kinzigtal=1]	Yes: reference category and stands for Kinzigtal
AGE	Numerical
LFU	Numerical
CCI	Numerical

B.2 Total numbers of days in hospital

Number of cases with valid los_total	807
Number of cases with valid cases of all independent variables	795
Number of cases after removing outliers and multicollinearity	760

The following tables provide tests of the model as a whole (Omnibus Test). The likelihood ratio chi-square provides a test of the overall model comparing this model to a model without any predictors (a "null" model). We can see that our model is a significant improvement over such a model, as p-value < 0.05.

In the Tests of Model Effects table, we see that the predictors "primary_chf", "region_Badalona", "region_Valencia", "region_ Kinzigtal", "region_Amadora" and "LFU" are statistically significant.

Omnibus Test

Likelihood Ratio Chi-Square	df	Sig.
292.494	12	0.000

Tests of Model Effects

Source	Type III Wald X^2	df	Sig.
(Intercept)	2.280	1.000	0.131
care_group	1.009	1.000	0.315
Gender	0.478	1.000	0.489
primary_chf	13.617	1.000	0.000
Primarydia	1.341	1.000	0.247
region_NorthernIreland	0.666	1.000	0.414
region_Badalona	45.054	1.000	0.000

	Type III		
Source	**Wald X^2**	**df**	**Sig.**
region_Valencia	104.554	1.000	0.000
region_Amadora	53.390	1.000	0.000
region_Kinzigtal	7.322	1.000	0.007
AGE	1.954	1.000	0.162
LFU	6.543	1.000	0.011
CCI	0.002	1.000	0.962

The table Parameter Estimates contains the negative binomial regression coefficients for each of the predictor variables along with their standard errors, Wald chi-square values, p-values and 95% confidence intervals for the coefficients.

Compared to patients who suffer from primary Congestive Heart Failure (primary_chf=1, reference category), the expected log count for patients not suffering from primary Congestive Heart Failure in the long term decreases by 0.41. At the same way, compared to patients from Badalona (reference category), the expected log count for patients not deriving from Badalona decreases by 1.54. Compared to patients from Valencia (reference category), the expected log count for patients not deriving from Valencia decreases by 2.38. Moreover, compared to patients from Amadora (reference category), the expected log count for patients not deriving from Amadora decreases by 1.66. Compared to patients from Kingigtal (reference category), the expected log count for patients not deriving from Kingigtal increases by 1.17. Additionally, the variable "LFU" has a coefficient of -0.002, which is statistically significant. This means that for each one-unit increase on length of follow-up, the expected log count decreases by 0.002. Finally, there isn’t enough information to estimate the dispersion coefficient, (Negative binomial).

Parameter Estimates

			95% Wald CI		Hypothesis Test				95% Wald CI for Exp(B)	
Parameter	**B**	**Std. Error**	**Lower**	**Upper**	**Wald X^2**	**df**	**Sig.**	**Exp(B)**	**Lower**	**Upper**
(Intercept)	3.792	1.205	1.430	6.153	9.905	1	0.002	44.327	4.180	470.076
[care_group=0]	-0.110	0.110	-0.325	0.105	1.009	1	0.315	0.896	0.723	1.110
[care_group=1]	0							1.000		
[gender=0]	0.069	0.099	-0.126	0.263	0.478	1	0.489	1.071	0.882	1.301
[gender=1]	0							1.000		
[primary_chf=0]	-0.415	0.113	-0.636	-0.195	13.617	1	0.000	0.660	0.529	0.823
[primary_chf=1]	0							1.000		
[primarydia=0]	-0.146	0.126	-0.394	0.101	1.341	1	0.247	0.864	0.674	1.107
[primarydia=1]	0							1.000		
[region_NorthernIreland=0]	-0.251	0.308	-0.855	0.352	0.666	1	0.414	0.778	0.425	1.422
[region_NorthernIreland=1]	0							1.000		
[region_Badalona=0]	-1.545	0.230	-1.997	-1.094	45.054	1	0.000	0.213	0.136	0.335
[region_Badalona=1]	0							1.000		
[region_Valencia=0]	-2.376	0.232	-2.831	-1.920	104.554	1	0.000	0.093	0.059	0.147
[region_Valencia=1]	0							1.000		
[region_Amadora=0]	-1.660	0.227	-2.105	-1.214	53.390	1	0.000	0.190	0.122	0.297
[region_Amadora=1]	0							1.000		
[region_Kinzigtal=0]	1.168	0.432	0.322	2.014	7.322	1	0.007	3.216	1.380	7.494
[region_Kinzigtal=1]	0							1.000		
AGE	0.010	0.007	-0.004	0.024	1.954	1	0.162	1.010	0.996	1.024
LFU	-0.002	0.001	-0.004	-0.001	6.543	1	0.011	0.998	0.996	0.999
CCI	0.001	0.025	-0.048	0.051	0.002	1		1.001	0.953	1.052

The variables "region_Campania" and "region_Sofia" have not been included in the analysis due to multicollinearity.

The analysis was conducted after recoding the remaining variables as follows:

Variable	Coding
[care_group=0]	Comparator
[care_group=1]	intervention is the reference category
[gender=0]	Male
[gender=1]	female is the reference category
[primary_chf=0]	No
[primary_chf=1]	Yes: reference category
[primarydia=0]	No
[primarydia=1]	Yes: reference category
[region_NorthernIreland=0]	No
[region_NorthernIreland=1]	Yes: reference category and stands for Northern Ireland
[region_Badalona=0]	No
[region_Badalona=1]	Yes: reference category and stands for Badalona
[region_Valencia=0]	No
[region_Valencia=1]	Yes: reference category and stands for Valencia
[region_Amadora=0]	No
[region_Amadora=1]	Yes: reference category and stands for Amadora
[region_Kinzigtal=0]	No
[region_Kinzigtal=1]	Yes: reference category and stands for Kinzigtal
AGE	Numerical
LFU	Numerical
CCI	Numerical

B.3 Total number of unplanned admissions

Number of cases with valid admission_unplanned	807
Number of cases with valid cases of all independent variables	795
Number of cases after removing outliers and multicollinearity	793

The following tables provide tests of the model as a whole (Omnibus Test). The likelihood ratio chi-square provides a test of the overall model comparing this model to a model without any predictors (a "null" model). We can see that our model is a significant improvement over such a model, as p-value < 0.05.

In the Tests of Model Effects table, we see that the predictors "primary_chf", "region_Badalona ", "region_Valencia", "region_Amadora” and "LFU” are statistically significant.

Omnibus Test

Likelihood Ratio Chi-Square	df	Sig.
122.355	12	0.000

Tests of Model Effects

Source	Type III Wald X^2	df	Sig.
(Intercept)	1.764	1	0.184
care_group	0.370	1	0.543
Gender	1.251	1	0.263
primary_chf	6.200	1	0.013
Primarydia	0.022	1	0.883
region_NorthernIreland	0.025	1	0.875
region_Badalona	26.982	1	0.000
region_Valencia	20.964	1	0.000
region_Amadora	26.200	1	0.000
region_Kinzigtal	0.038	1	0.845
AGE	0.076	1	0.783
LFU	12.118	1	0.000
CCI	0.010	1	0.920

The table Parameter Estimates contains the negative binomial regression coefficients for each of the predictor variables along with their standard errors, Wald chi-square values, p-values and 95% confidence intervals for the coefficients.

Compared to patients who suffer from primary Congestive Heart Failure (primary_chf=1, reference category), the expected log count for patients not suffering from primary Congestive Heart Failure in the long term decreases by 0.37. At the same way, compared to patients from Badalona (reference category), the expected log count for patients not deriving from Badalona decreases by 1.99. Compared to patients from Valencia (reference category), the expected log count for patients not deriving from Valencia decreases by 1.83. Moreover, compared to patients from Amadora (reference category), the expected log count for patients not deriving from Amadora decreases by 1.96. Additionally, the variable "LFU" has a coefficient of -0.004, which is statistically significant. This means that for each one-unit increase on length of follow-up, the expected log count decreases by 0.004. Finally, there isn't enough information to estimate the dispersion coefficient, (Negative binomial).

Parameter Estimates

Parameter	B	Std. Error	95% Wald CI		Hypothesis Test			Exp(B)	95% Wald CI for Exp(B)	
			Lower	Upper	Wald X^2	df	Sig.		Lower	Upper
(Intercept)	4.393	1.841	0.785	8.000	5.696	1	0.017	80.865	2.193	2982.155
[care_group=0]	0.095	0.156	-0.211	0.400	0.370	1	0.543	1.099	0.810	1.492
[care_group=1]	0							1.000		
[gender=0]	0.148	0.132	-0.111	0.407	1.251	1	0.263	1.159	0.895	1.503
[gender=1]	0							1.000		
[primary_chf=0]	-0.373	0.150	-0.667	-0.079	6.200	1	0.013	0.688	0.513	0.924
[primary_chf=1]	0							1.000		
[primarydia=0]	-0.026	0.174	-0.367	0.316	0.022	1	0.883	0.975	0.692	1.372
[primarydia=1]	0							1.000		
[region_NorthernIreland=0]	0.082	0.518	-0.933	1.097	0.025	1	0.875	1.085	0.393	2.994
[region_NorthernIreland=1]	0							1.000		
[region_Badalona=0]	-1.989	0.383	-2.740	-1.239	26.982	1	0.000	0.137	0.065	0.290
[region_Badalona=1]	0							1.000		

Parameter	B	Std. Error	95% Wald CI		Hypothesis Test			Exp(B)	95% Wald CI for Exp(B)	
			Lower	Upper	Wald X^2	df	Sig.		Lower	Upper
[region_Valencia=0]	-1.826	0.399	-2.608	-1.045	20.964	1	0.000	0.161	0.074	0.352
[region_Valencia=1]	0							1.000		
[region_Amadora=0]	-1.965	0.384	-2.718	-1.213	26.200	1	0.000	0.140	0.066	0.297
[region_Amadora=1]	0							1.000		
[region_Kinzigtal=0]	-0.106	0.542	-1.168	0.957	0.038	1	0.845	0.900	0.311	2.603
[region_Kinzigtal=1]	0							1.000		
AGE	0.003	0.009	-0.016	0.021	0.076	1	0.783	1.003	0.985	1.021
LFU	-0.004	0.001	-0.007	-0.002	12.118	1	0.000	0.996	0.993	0.998
CCI	-0.003	0.034	-0.070	0.063	0.010	1	0.920	0.997	0.933	1.065

The variables "region_Campania" and "region_Sofia" have not been included in the analysis due to multicollinearity.

The analysis was conducted after recoding the remaining variables as follows:

Variable	Coding
[care_group=0]	Comparator
[care_group=1]	intervention is the reference category
[gender=0]	Male
[gender=1]	female is the reference category
[primary_chf=0]	No
[primary_chf=1]	Yes: reference category
[primarydia=0]	No
[primarydia=1]	Yes: reference category
[region_NorthernIreland=0]	No
[region_NorthernIreland=1]	Yes: reference category and stands for Northern Ireland
[region_Badalona=0]	No
[region_Badalona=1]	Yes: reference category and stands for Badalona
[region_Valencia=0]	No
[region_Valencia=1]	Yes: reference category and stands for Valencia
[region_Amadora=0]	No
[region_Amadora=1]	Yes: reference category and stands for Amadora
[region_Kinzigtal=0]	No
[region_Kinzigtal=1]	Yes: reference category and stands for Kinzigtal
AGE	Numerical
LFU	Numerical
CCI	Numerical

B.4 Total number of days of unplanned admissions in hospital

Number of cases with valid los_unplanned	807
Number of cases with valid cases of all independent variables	795
Number of cases after removing outliers and multicollinearity	764

The following tables provide tests of the model as a whole (Omnibus Test). The likelihood ratio chi-square provides a test of the overall model comparing this model to a model without any predictors (a "null" model). We can see that our model is a significant improvement over such a model, as p-value < 0.05.

In the Tests of Model Effects table, we see that the predictors "gender", "primary_chf", "region_NorthernIreland", "region_Valencia", "region_Amadora", " region_Kinzigtal" and "LFU" are statistically significant.

Omnibus Test

Likelihood Ratio Chi-Square	df	Sig.
469.800	12	0.000

Tests of Model Effects

	Type III		
Source	Wald X^2	df	Sig.
(Intercept)	4.178	1	0.041
care_group	0.081	1	0.776
Gender	4.302	1	0.038
primary_chf	23.275	1	0.000
Primarydia	3.685	1	0.055
region_NorthernIreland	9.889	1	0.002
region_Badalona	0.000	1	0.991
region_Valencia	87.108	1	0.000
region_Amadora	9.812	1	0.002
region_Kinzigtal	6.994	1	0.008
AGE	2.559	1	0.110
LFU	38.008	1	0.000
CCI	0.894	1	0.344

The table Parameter Estimates contains the negative binomial regression coefficients for each of the predictor variables along with their standard errors, Wald chi-square values, p-values and 95% confidence intervals for the coefficients.

Compared to males (reference category), the expected log count for females increases by 0.26. Compared to patients who suffer from primary Congestive Heart Failure (primary_chf=1, reference category), the expected log count for patients not suffering from primary Congestive Heart Failure in the long term decreases by 0.71. Moreover, compared to patients from Northern Ireland (reference category), the expected log count for patients not deriving from Northern Ireland increases by 1.25. Compared to patients from Valencia (reference category), the expected log count for patients not deriving from Valencia decreases by 2.42. At the same way, compared to patients from Amadora (reference category), the expected log count for patients not deriving from Amadora decreases by 0.82. Compared to patients from Kingigtal (reference category), the expected log count for patients not deriving from Kingigtal increases by 1.69. Additionally, the variable "LFU" has a coefficient of -0.007, which is statistically significant. This means that for each one-unit increase on length of follow-up, the expected log count decreases by 0.007. Finally, there isn't enough information to estimate the dispersion coefficient, (Negative binomial).

Parameter Estimates

			95% Wald CI		Hypothesis Test				95% Wald CI for Exp(B)	
Parameter	B	Std. Error	Lower	Upper	Wald X^2	df	Sig.	Exp(B)	Lower	Upper
(Intercept)	2.480	1.494	-0.448	5.408	2.755	1	0.097	11.938	0.639	223.128
[care_group=0]	0.040	0.140	-0.234	0.314	0.081	1	0.776	1.041	0.791	1.369
[care_group=1]	0							1.000		
[gender=0]	0.258	0.124	0.014	0.502	4.302	1	0.038	1.294	1.014	1.652
[gender=1]	0							1.000		
[primary_chf=0]	-0.714	0.148	-1.004	-0.424	23.275	1	0.000	0.490	0.366	0.654
[primary_chf=1]	0							1.000		
[primarydia=0]	-0.309	0.161	-0.624	0.006	3.685	1	0.055	0.734	0.536	1.006
[primarydia=1]	0							1.000		
[region_NorthernIreland=0]	1.248	0.397	0.470	2.025	9.889	1	0.002	3.482	1.600	7.577
[region_NorthernIreland=1]	0							1.000		
[region_Badalona=0]	-0.003	0.285	-0.562	0.555	0.000	1	0.991	0.997	0.570	1.743
[region_Badalona=1]	0							1.000		
[region_Valencia=0]	-2.419	0.259	-2.928	-1.911	87.108	1	0.000	0.089	0.054	0.148
[region_Valencia=1]	0							1.000		
[region_Amadora=0]	-0.822	0.262	-1.336	-0.308	9.812	1	0.002	0.440	0.263	0.735
[region_Amadora=1]	0							1.000		
[region_Kinzigtal=0]	1.691	0.639	0.438	2.944	6.994	1	0.008	5.424	1.549	18.992
[region_Kinzigtal1]	0							1.000		
AGE	-0.014	0.009	-0.031	0.003	2.559	1	0.110	0.986	0.970	1.003
LFU	-0.007	0.001	-0.010	-0.005	38.008	1	0.000	0.993	0.990	0.995
CCI	-0.029	0.031	-0.090	0.032	0.894	1	0.344	0.971	0.914	1.032

The variables " region_Campania" and "region_Sofia" have not been included in the analysis due to multicollinearity.

The analysis was conducted after recoding the remaining variables as follows:

Variable	Coding
[care_group=0]	Comparator
[care_group=1]	intervention is the reference category
[gender=0]	Male
[gender=1]	female is the reference category
[primary_chf=0]	No
[primary_chf=1]	Yes: reference category
[primarydia=0]	No
[primarydia=1]	Yes: reference category
[region_NorthernIreland=0]	No
[region_NorthernIreland=1]	Yes: reference category and stands for Northern Ireland
[region_Badalona=0]	No
[region_Badalona=1]	Yes: reference category and stands for Badalona
[region_Valencia=0]	No
[region_Valencia=1]	Yes: reference category and stands for Valencia
[region_Amadora=0]	No
[region_Amadora=1]	Yes: reference category and stands for Amadora
[region_Kinzigtal=0]	No

Variable	Coding
[region_Kinzigtal=1]	Yes: reference category and stands for Kinzigtal
AGE	Numerical
LFU	Numerical
CCI	Numerical

Appendix C: Interview guide for care recipients

We recruit care recipients who need integrated care and rehabilitation in collaboration between social & health care professionals. Preferably the care recipients should represent different types (e.g. regarding, gender, age etc.).

Please conduct interviews with a minimum of three care recipient. It is suggested that you start by explaining to the end-user the aims of the interview (to explore how technology can support patient care processes in care, treatment and rehabilitation across sectors), and that they will be anonymous in the communication of findings from the BeyondSilos project. The interview is planned to last between 45-60 minutes. Please take notes during the interview. You will need your notes for a description of the cases (please see template in Appendix A.5). You also have to fill in **Table 41** in English for each of the care recipient and send it to Signe Daugbjerg.

Table 41: Interview guide for care recipient

End-user nr: Sex?	
Question	**Notes for answers**
Presentation	
1. Could you please shortly present yourself? (prior job, education, family, etc.) ?	
2. How many persons 18 years and above lives in your household besides you?	
3. Could you please explain shortly how and when did your illness occur?	
Everyday life	
3. Please describe your everyday life which activities are you able to do your-self and in which do you need or ask help from other people? How often do you undertake these activities weekly? • **Today's rhythm** • **Work** • **Leisure** • **Activities** • **Hobbies**	
5. How often (weekly, monthly, yearly) do you see other family members or friends not living in the same household?	
Use of technology	
6. Do you use a computer? Mobile phone? Tablet? Other technologies?	
7. If yes, what do you use the technology for?	

End-user nr: Sex?	
Question	**Notes for answers**
Management of your disease / rehabilitation programme by the use of ICT	
8. How is the management of your disease/rehabilitation program planned? Are there clear goals for your progress?	
9. What activities have been planned so far? Activities such as hospital visits, diagnostics, physical or other therapist, health care centre visits, social care centre visits, fitness Centre, etc. ?	
10. Please explain how is the technology being used for supporting your disease/ rehabilitation? • **Are the healthcare or social care professionals using the ICT in collaboration with you?** • **Do you have access to your health or social data? Can you see your own record? If so, what do you use the information's for? Does anyone else check your own record, such as your family members, caregivers?** • **In your point of view, what are the benefits or downsides using ICT to coordinate, plan and communicate care/ rehabilitation for you?**	
Coordination of your care	
11. Which healthcare or social care professionals or voluntaries have you had contact / cooperation with during your illness? (etc. doctors, nurses, GPs, social workers, physiotherapist, church members, patient organizations)	
12. Thinking about all the health and/or social services you have used in the last 3-4 months, how do you experience or think your care has been coordinated (For example, the way different doctors, nurses, social workers and organisations work together)?	

End-user nr: Sex?	
Question	**Notes for answers**
13. Have you noticed any difference in the overall care you have been receiving, since you entered in the BeyondSilos program? And could you please describe which changes, if any? **If yes,** • **Does the new integrated treatment help you understand your illness? How?** • **Does the new treatment help you cope with your illness? How?** • **Does the new treatment make you more confident about your health?**	

Appendix D: Interview guide for professionals

A minimum of six or more healthcare professionals / social workers should be identified for the interviews. In order to save time, you can consider performing the interviews online or by telephone. We recommend that the interview lasts 30 minutes and that you afterward use 30 minutes to write a summary of the interview. You will have to use your notes for a case description on how you have worked with ICT to integrated care (see Appendix A.5). You also have to fill in **Table 42** in English for each of the professionals and send it to Signe Daugbjerg.

Table 42: Interview guide for professionals

PROFESSIONAL 1	
1. Please introduce yourself shortly (job & education)?	
2. How long have you worked in your current job?	
3. What is your age?	
4. Can you describe the ICT solution that you are using?	
5. Do you think it has supported the integrated care? Please explain.	
6. Has your workflow changed since the introduction of the ICT? If yes, please describe how: • **Do you now delegate more responsibility to others?** • **Do you now have more responsibility delegated to you?**	
7. Has the ICT supported you in your collaboration with the patient? If yes, please describe how:	
8. Has the ICT solution had any impact on the daily work with the patients? If yes – will you please describe how? What have been the benefits and the pitfalls seen from your perspective?	
9. How have you used the ICT solution in your collaboration with healthcare or social care professionals: o **Within the hospital** o **Between hospital and social care** o **Between hospital and GP´s ?** o **Between Social care and GP's?**	
10. How would you describe the collaboration in implementing the ICT tool in your organisation?	
11. How would you describe the collaboration by using the ICT as a tool to coordinate, plan and communicate about the patient?	
12. How would you characterize the changes in the collaboration after the ICT has been implemented	
13. Have you experienced any changes in the communication between different parts of your organization or with other organisations?	
14. Please let us know any other comments you may have about the integrated care using the ICT solution.	

Appendix E: Questionnaires

E.1 Barthel Index of Activities of Daily Living

Scores range between 0 – 100' a higher score indicates better functionality.

Activity **Score**

FEEDING
0 = unable
5 = needs help cutting, spreading butter, etc., or requires modified diet
10 = independent ______

BATHING
0 = dependent
5 = independent (or in shower) ______

GROOMING
0 = needs to help with personal care
5 = independent face/hair/teeth/shaving (implements provided) ______

DRESSING
0 = dependent
5 = needs help but can do about half unaided
10 = independent (including buttons, zips, laces, etc.) ______

BOWELS
0 = incontinent (or needs to be given enemas)
5 = occasional accident
10 = continent ______

BLADDER
0 = incontinent, or catheterized and unable to manage alone
5 = occasional accident
10 = continent ______

TOILET USE
0 = dependent
5 = needs some help, but can do something alone
10 = independent (on and off, dressing, wiping) ______

TRANSFERS (BED TO CHAIR AND BACK)
0 = unable, no sitting balance
5 = major help (one or two people, physical), can sit
10 = minor help (verbal or physical)
15 = independent ______

MOBILITY (ON LEVEL SURFACES)
0 = immobile or < 50 yards
5 = wheelchair independent, including corners, > 50 yards
10 = walks with help of one person (verbal or physical) > 50 yards
15 = independent (but may use any aid; for example, stick) > 50 yards ______

STAIRS
0 = unable
5 = needs help (verbal, physical, carrying aid)
10 = independent ______

TOTAL (0–100): ______

E.2 Instrumental Activities of Daily Living Scale (IADL)

A. Ability to use telephone

1. Operates telephone on own initiative; looks up and dials numbers, etc.	1
2. Dials a few well-known numbers	1
3. Answers telephone but does not dial	1
4. Does not use telephone at all.	0

B. Shopping

1. Takes care of all shopping needs independently	1
2. Shops independently for small purchases	0
3. Needs to be accompanied on any shopping trip.	0
4. Completely unable to shop.	0

C. Food Preparation

1. Plans, prepares and serves adequate meals independently	1
2. Prepares adequate meals if supplied with ingredients	0
3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet.	0
4. Needs to have meals prepared and served.	0

D. Housekeeping

1. Maintains house alone or with occasional assistance (e.g. “heavy work domestic help”)	1
2. Performs light daily tasks such as dishwashing, bed making	1
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.	1
4. Needs help with all home maintenance tasks.	1
5. Does not participate in any housekeeping tasks.	0

E. Laundry

1. Does personal laundry completely	1
2. Launders small items; rinses stockings, etc.	1
3. All laundry must be done by others.	0

F. Mode of Transportation

1. Travels independently on public transportation or drives own car.	1
2. Arranges own travel via taxi, but does not otherwise use public transportation.	1
3. Travels on public transportation when accompanied by another.	0
4. Travel limited to taxi or automobile with assistance of another.	0
5. Does not travel at all	0

G. Responsibility for own medications

1. Is responsible for taking medication in correct dosages at correct time.	1
2. Takes responsibility if medication is prepared in advance in separate dosage.	0
3. Is not capable of dispensing own medication.	0

H. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income.	1
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.	1
3. Incapable if handling money.	0

Source: *Lawton, M.P., and Brody, E.M. “Assessment of older people: Self-maintaining and instrumental activities of daily living.” Gerontologist 9:179-186, (1969).*

E.3 Geriatric Depression Scale (GDS)

No.	Question	Answer	Score
1.	Are you basically satisfied with your life?	Yes / ***No***	
2.	Have you dropped many of your activities and interests?	***Yes*** / No	
3.	Do you feel that your life is empty?	***Yes*** / No	
4.	Do you often get bored?	***Yes*** / No	
5.	Are you in good spirits most of the time?	Yes / ***No***	
6.	Are you afraid that something bad is going to happen to you?	***Yes*** / No	
7.	Do you feel happy most of the time?	Yes / ***No***	
8.	Do you often feel helpless?	***Yes*** / No	
9.	Do you prefer to stay at home, rather than going out and doing new things?	***Yes*** / No	
10.	Do you feel you have more problems with memory than most people?	***Yes*** / No	
11.	Do you think it is wonderful to be alive?	Yes / ***No***	
12.	Do you feel pretty worthless the way you are now?	***Yes*** / No	
13.	Do you feel full of energy?	Yes / ***No***	
14.	Do you feel that your situation is hopeless?	***Yes*** / No	
15.	Do you think that most people are better off than you are?	***Yes*** / No	
		TOTAL	