Summary of Deployment site progress [D.8.1 update]

Scotland, RSD, FVG and Aragon [Work Package no. 8]

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Document information

Abstract

This document gives the status of progress so far in WP8 – Evaluation.

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Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise.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

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1. Introduction

1.1 Purpose of the document

This document gives the status of progress so far in WP8 – Evaluation. It is intended for deployment sites that have not already started working on the evaluation aspects of SmartCare, for them to learn from the sites that have gone through the work and as a point of departure to finish the planning phase of evaluating SmartCare.

1.2 Background

The deployment sites in Region of Southern Denmark (RSD), Scotland, FVG and Aragon have been through the process of establishing the necessary aspects of carrying out their data collection.

Originally, the D8.1 Evaluation Framework was and is the point of departure for all deployment sites. The document describes the overall aspects of SmartCare that need to be similar for all sites. The first four deployment sites have since worked at adjusting the plans to their local settings, and making the planned measures of outcomes more specific, including selecting the instruments to use for the common outcomes. All sites have additional individual outcomes that are related to the specific local circumstances and end-users' characteristics. Insofar as has been possible, deployment sites have also tried to agree on instruments used for these additional outcomes.

The high level of agreement across sites means that a lot of the outcomes that will be measured in SmartCare can be compared across geographic boarders, which is a clear advantage. Nevertheless, this does not mean that other instruments or outcomes are excluded from use.

The following sections of this document describe the process that has taken place between January 2014 and April 2014. It clearly identifies which parts need specific repetition for the next deployment sites; in section 8, there is a summary of the tasks ahead.

1.3 Glossary

AKD   Anne-Kirstine Dyrvig

RSD   Region of Southern Denmark

FVG   Friuli Venezia Giulia

TA   Technical Annex

2. Preliminary evaluation steps

First of all, setting up the team from the outset is an advantage; especially when the time comes for analysis, having had a statistician on the team from the beginning will show benefits. Thus, the first steps that need to be specified for deployment sites are:

- Anticipated start date (inclusion of first end-user into the SmartCare service).

- Set up of local evaluation team including:
  o The person responsible for collecting data in practice.
  o A statistician.
  o Someone with knowledge of the SmartCare services.

3. Deployment site evaluation planning

Next, practically applicable strategies for data collection need to be specified. That means that the local evaluation team decides on the overall plan for the evaluation, including:

- Sample size estimation.

- Length of follow up period.

- Selection of control group.

During discussion on these aspects, it should be kept in mind how many end-users were originally mentioned in the TA. In addition, the availability of data for each individual needs to be known, particularly regarding the choice of control group. If historic controls are chosen, it is highly important that all necessary data are available already on an individual basis for the population considered.

The table below summarises the planning choices made by the first deployment sites.

Table 1: Evaluation planning for the first deployment sites

Deployment site	Evaluation sample size (Intervention / control)	Total SmartCare population	Control selection	Follow-up (months)				
				1	3	6	12	18
RSD	1250 (625/625)	2000	Geographic area, consecutively included, parallel		X	X		
Scotland	200 (100/100)	6000	Historic data supplemented			X	X	
FVG	200 (100/100)		Randomisation		X	X		
Aragon	300 (150/150)		Randomisation	X	X	X	X	X

4. Outcome measures and data collection

The outcomes that need to be measured in SmartCare are a combination of common measures and locally chosen measures. For D8.1, a list of indicators was elaborated as an inspiration. The list of indicators has since worked as a point of departure for deployment sites to pick and choose locally relevant outcomes, as well as a reminder of the mandatory outcomes that all deployment sites need to measure.

The list of indicators, therefore, is rather long. While going through it, it is recommended to check whether a variable is indicated as mandatory or voluntary. In the common dataset, one indicator for each (relevant) MAST domain has been picked out in order to reduce the burden related to data collection.

Table 2: Inspirational table for outcome measures

Measurement	Respondent / target group	Level of data	Level of detail	Mandatory / voluntary	Collection method	Timing of measurement	Notes
1. Overall service effectiveness and specific outcome measures							
Number of contacts, healthcare services HOSPITAL	Citizen	Individual level	Number, dates and causes	M	Registries	Continuous	Type of contact: physical, telephone, email
Number of contacts, healthcare services GP	Citizen	Individual level					Type of contact: physical, telephone, email
Number of contacts, healthcare services MUNICIPALITY – care manager							Type of contact: physical, telephone, email
Unplanned contacts, HOSPITAL	Citizen / client / carer	Individual level	Number	V	Registries	Baseline / mid-term / exit	Unplanned contacts is chosen because it is 1) easy to establish (was there an unplanned contact or not), and 2) it reflects both the aim of the interventions in clinical terms but also safety issues, organisational and economic aspects. At each site, the exact meaning and operationalisation of this outcome measure needs to be defined.
Number of contacts, social care services	Citizen / client / carer	Individual level	Number	M	Registries	Baseline / mid-term / exit	Total number of contacts is 1) easy to establish (was there a contact or not), and 2) it is available in all sites

Measurement	Respondent / target group	Level of data	Level of detail	Mandatory / voluntary	Collection method	Timing of measurement	Notes
Unplanned contacts, social care services	Citizen / client / carer	Individual level	Number	V	Registries	Baseline / mid-term / exit	Unplanned contacts is chosen because it is 1) easy to establish (was there an unplanned contact or not), and 2) it reflects both the aim of the interventions in clinical terms but also safety issues, organisational and economic aspects. At each site, the exact meaning and operationalisation of this outcome measure needs to be defined.
Number of contacts, volunteer sector services	Citizen / client / carer	Individual level	Number	M, if relevant in setting	Registries	Baseline / mid-term / exit	Total number of contacts is 1) easy to establish (was there a contact or not), and 2) it is available in all sites
Unplanned contacts, volunteer sector services	Citizen / client / carer	Individual level	Number	V	Registries	Baseline / mid-term / exit	Unplanned contacts is chosen because it is 3) easy to establish (was there an unplanned contact or not), and 4) it reflects both the aim of the interventions in clinical terms but also safety issues, organisational and economic aspects. At each site, the exact meaning and operationalisation of this outcome measure needs to be defined.
1.a Disease specific health status measures							
Blood pressure	Citizen / client	Individual level	Number	V	Registries	Baseline / mid-term / exit	Indicator for health status
Blood glucose	Citizen / client	Individual level	Number	V	Registries	Baseline / mid-term / exit	Indicator for health status (diabetics only)
Cholesterol	Citizen / client	Individual level	Number	V	Registries	Baseline / mid-term / exit	Indicator for health status
Anxiety	Citizen / client	Individual level	Scale	V	Questionnaire or interview	Baseline / mid-term / exit	Indicator for health status
Status/severity of primary condition	Citizen / client	Individual level	Scale or number	V	Registries	Baseline / mid-term / exit	Predictor of health outcome
1.b Generic health related / functional quality of life							
WHOBREF	Citizen / client	Individual level	Scale	V	Questionnaire or interview	Baseline / exit	Might be affected by the intervention

Measurement	Respondent / target group	Level of data	Level of detail	Mandatory / voluntary	Collection method	Timing of measurement	Notes
Barthel	Citizen / client	Individual level	Scale	V	Clinical measurement	Baseline / exit	Indicator for health status
Timed up & go	Citizen / client	Individual level	Number	V	Clinical measurement	Baseline / exit	Indicator for health status
CASP-19 family carer QoL	Carers	Individual level	Scale	V	Questionnaire or interview	Baseline / exit	The CASP-19 is used to specifically measure QoL of family carers. The measure has four domains: control, autonomy, pleasure and self-realisation. The scale contains 19 items.
1.c Psychological measures							
Anxiety and depression according to HADS	Citizen / client	Individual level	Number	V	Questionnaire or interview	Baseline / exit	HADS is used to determine the levels of anxiety and depression in end users. It is a 14-item scale. Seven of the items relate to anxiety and seven related to depression.
Depression according to GDS	Citizen / client	Individual level	Number	V	Questionnaire or interview	Baseline / exit	The Geriatric Depression Scale-15 (GDS-15) is a short, 15-item instrument specifically designed to assess depression in geriatric populations. Its items require a yes/no response. The Geriatric Depression Scale was first introduced by Yesavage et al. in 1983, and the short form (GDS-15) was developed by Sheikh and Yesavage in 1986.
Isolation according to Perceived Isolation Questionnaire	Citizen / client	Individual level	Number	V	Questionnaire or interview	Baseline / exit	Previous research has identified a wide range of indicators of social isolation that pose health risks, including living alone, having a small social network, infrequent participation in social activities, and feelings of loneliness.
Carer burden according to ZBI (short version)	Carers	Individual level	Number	V	Questionnaire or interview	Baseline / exit	The Zarit Burden Interview was developed to measure subjective burden among family carers of adults with dementia. Bédard et al produced a short version consisting of 12 items, with results comparable to the full version. Cronbach's α for the 12-item version is 0.88.
Carer burden according to CADI-CASI-CAMI suite	Carers	Individual level	Number	V	Questionnaire or interview	Baseline / exit	Carers are also assessed for difficulties, satisfaction and management in caring using the CADI-CASI-CAMI suite. The CADI-CASI-CAMI suite is a collection of three instruments used to assess family carers' perceptions of difficulty, satisfaction and management (coping strategies).

Measurement	Respondent / target group	Level of data	Level of detail	Mandatory / voluntary	Collection method	Timing of measurement	Notes
2. Safety							
Deaths	Citizen / client	Individual level	Yes/no (dichotomous)	M	Registries	Exit	Easy to establish, common as adverse outcome
3. End user / client / carer perspectives							
End user empowerment	Citizen / client / carer	Individual level	Scale for each question	M	Questionnaire	Exit	Reflects the aim of SmartCare
End user satisfaction	Citizen / client / carer	Individual level	Scale for each question	M	Questionnaire, IFIC	Exit	This would be based on the eCare Client Impact Survey developed in CommonWell and INDEPENDENT.
End user perception of integration	End-users	Individual level	One question with visual scale? Ingo, please correct me if this is wrong	M	Questionnaire	Exit	SmartCare developed tool
4. Economic measures							
Efforts related to service development & implementation	Citizen / client / carer Service providers	Individual or organisational level	Number	M	Various	Exit Implementation and pilot phase	To support the design and implementation of viable and sustainable services. To produce supportive data for internal decision making processes. To allow for an overall, post-hoc assessment of socio-economic impacts.
Efforts related to service operation or use	Citizen / client / carer Service providers	Individual or organisational level	Number	M	Various	Exit Implementation and pilot phase	As above.
Equipment cost	Service providers	Organisational level	Number	M	Various	Implementation and pilot phase	As above.
Service effectiveness benefits	Service providers	Organisational level	Number	M	Various	Implementation and pilot phase	As above.
Service efficiency benefits	Service providers	Organisational level	Number	M	Various	Implementation and pilot phase	As above.
Revenue streams	Service providers	Organisational level	Number	M	Various	Implementation and pilot phase	As above.
Willingness to pay	Citizen / client / carer	Individual level	Scale	V	Questionnaire	Exit	Relevant if a service fee payable by end user / client / carer is considered to become part of the revenue model.

Measurement	Respondent / target group	Level of data	Level of detail	Mandatory / voluntary	Collection method	Timing of measurement	Notes
5. Organisational impact measures							
Impacts on staff	Service providers: staff members	Organisational level	Scales, qualitative	M	Questionnaire or interview	Pilot end	Key measures to understand the organisational changes caused by the new service, as well as to get a better understanding of what was actually achieved through the integration of different service silos. Can also capture where staff members and organisational decision makers are (still) not satisfied with the result.
Impacts on organisations	Service providers: staff members	Organisational level	Scales, qualitative	M	Questionnaire or interview	Pilot end	As above.
Service integration aspects	Service providers: staff members	Organisational level	Scales, qualitative	M	Questionnaire or interview	Pilot end	As above.
Mainstreaming potential and sustainability	Service providers	Organisational level	Scales, qualitative	M	Questionnaire or interview	Pilot end	As above.
6. Possible confounders / control variables							
Date of birth	Citizen / client / carer	Individual level	YYYY-MM-DD	M	Registries or interview	Inclusion	Age is a strong predictor of any health outcome
Gender	Citizen / client / carer	Individual level	Male/ female	M	Registries or interview	Inclusion	Gender is very often related to health outcomes
Level of education	Citizen / client / carer	Individual level	Categories	M	Registries or interview	Inclusion	Level of education is a strong predictor of any health outcome. Generally, it is said that one Euro given to education increases the level of health more than one Euro given to healthcare. Categories are important and have to be used in a similar way throughout pilots.
Marital status	Citizen / client / carer	Individual level	Categories	M	Registries or interview	Inclusion	Marital status is a strong predictor of health outcomes. It is better to be married than being single. Categories are important and have to be used in a similar way throughout pilots.

Measurement	Respondent / target group	Level of data	Level of detail	Mandatory / voluntary	Collection method	Timing of measurement	Notes
Ethnicity	Citizen / client / carer	Individual level	Categories	V	Questionnaire or interview	Inclusion	Ethnicity is strongly related to health outcomes
Main work status (last 12 months)	Citizen / client / carer	Individual level	Categories	V	Questionnaire or interview	Inclusion	Work status is being recognised as a strong indicator of health outcome. It turns out that people belong to the social group in which they work rather than the one in which they are educated. Categories are important and have to be used in a similar way throughout pilots.
People older than 18 living in household	Citizen / client / carer	Individual level	Number	V	Questionnaire or interview	Inclusion	Indicator for the level of informal care received.
Household income	Citizen / client / carer	Individual level	Number	V	Questionnaire or interview	Inclusion	Necessary if willingness-to-pay is analysed.
Daily tobacco use	Citizen / client	Individual level	Dichotomous	V	Questionnaire or interview	Inclusion	Indicator for health status
Frequency of alcohol (12 months)	Citizen / client	Individual level	Categories	V	Questionnaire or interview	Inclusion	Indicator for health status
Height (CM)	Citizen / client	Individual level	Number	V	Questionnaire or interview	Inclusion	Indicator for health status
Weight (Kg)	Citizen / client	Individual level	Number	V	Questionnaire or interview	Inclusion	Indicator for health status
Co-morbidity	Citizen / client	Individual level	ICD-10 codes	V	Questionnaire or interview	Inclusion	Indicator for health status, highly relevant for the usability of results after finishing pilots.

5. Common data collection instruments

A number of the outcomes are to be measured using different scales. Therefore, questionnaires have been reviewed in terms of deciding which are most appropriate for the SmartCare project. Since additional outcomes are also allowed, some sites have decided on extra questionnaires, which are also aligned among the deployment sites so far.

The table below shows the choices on instruments for data collection.

Table 3: Instruments for outcome measures

Deployment site	Generic HRQoL and function		Psychological		End-user perspectives			Organisational aspects	Other				
	WHOBREF	Timed up&go	Social isolation (Alodia social risk assessment)	HADS	Empower-ment (PAM)	Satisfac-tion (eCCIS)	Perception of integration (SmartCare)	Staff perception (SmartCare combined from previous projects)	Carer burden (Zarit)	Perception of family function (Apgar)	Social risk assessment (Alodia & Red Cross)	Heart failure q'aire	Usability (SUS)
RSD	(X)		X		X	X	X	X					
Scotland	X	X	X		X	X	X	X					
FVG	X		X	X	X	X	X	X				X	
Aragon	X		X	X	X	X	X	X	X	X	X		

6. Database (CRF)

Based on local plans, a common database with local areas for inserting data will be developed (by AKD).

7. Contact between WP 8 & deployment sites

Weekly on Thursdays, each pilot site has been given a dedicated hourly time slot for discussion of current issues. Time slots are divided among the 1st wave deployment sites as follows:

> 10:00-11:00: Scotland
>
> 11:00-12:00: Italy
>
> 12:00-13:00: Spain
>
> 13:00-14:00: Denmark

8. Time plan for 2014

The time plan is based on the subjects that will most likely be discussed during the Skype meetings. In addition, time will be dedicated to discussion of current local issues.

Week	2	3	4	5	6	7
Milestone	Statistician Data collection responsible	Follow up and timing of measurement	Follow up and timing of measurement	Variables and current availability	Variables and current availability	Data collection methods
Status						

Week	8	9	10	11	12	13
Milestone	Data collection methods	Time slack	Data collection methods	Data collection methods	Data collection methods	Data collection methods
Status						

Week	14	15	16	17	18
Milestone	Database construction/ testing	Database construction/ testing	Database testing	Time slack	Inclusion begins
Status					

Shortly after the Skype meetings, AKD will develop an overview of current status and distribute among pilot sites, so all pilot sites are aware of current status in other pilots.