FP7-ICT-611140 CARRE

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D.8.1. Project Presentation & Web Site

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Disclaimer

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Document Control Page

Project

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Type:	STREP
Start:	1 November 2013
End:	31 October 2016
Programme:	FP7-ICT-2013.5.1
Website:	http://www.carre-project.eu/

Deliverable

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Document Revision History

Version	Date	Modifications	Contributors
v01	24 Nov 2013	new content	E. Kaldoudi
v02	28 Nov 2013	review comments by John Domingue inserted review comments by Enjie Liu inserted review comments by Domantas Stundys inserted review comments by Arunas Lukosevicius inserted inserted short CARRE summary in executive summary deleted contractual obligations page (former p. 8) improved graphics for figure 6: site map project presentation ppt: slide 02: figure improved & 'cardiorenal' inserted slide 20: corrected slide 21: logos embossed 1-slide project presentation ppt: logos embossed human in the centre slightly enlarged	E. Kaldoudi

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Executive Summary

The goal of this document is twofold:

(a) To give descriptions of the CARRE project for different purposes:

- CARRE facts: summarizing the main figures for CARRE;
- CARRE in a nutshell: which will be used as a project overview and can also be included in a variety of documents produced by the consortium, EC or third parties;
- CARRE logo;
- CARRE presentation: a slide show with an overview of the project;
- CARRE 1-slide presentation: a one-slide summary of the project;
- CARRE press release: to be used as a main introductory text for disseminating CARRE in the press;

(b) To describe actions taken for the CARRE web presence, including:

- project web site;
- project presence in social media, e.g. Twitter, Facebook, LinkedIn, SlideShare, etc.

About CARRE

CARRE is an EU FP7-ICT funded project with the goal to provide innovative means for the management of comorbidities (multiple co-occurring medical conditions), especially in the case of chronic cardiac and renal disease patients or persons with increased risk of such conditions.

Sources of medical and other knowledge will be semantically linked with sensor outputs to provide clinical information personalised to the individual patient, so as to be able to track the progression and interactions of comorbid conditions. Visual analytics will be employed so that patients and clinicians will be able to visualise, understand and interact with this linked knowledge and also take advantage of personalised empowerment services supported by a dedicated decision support system.

The ultimate goal is to provide the means for patients with comorbidities to take an active role in care processes, including self-care and shared decision-making, and also to support medical professionals in understanding and treating comorbidities via an integrative approach.

Terms and Definitions

The following are definitions of terms, abbreviations and acronyms used in this document.

Term	Definition
Apache HTTP server	Open-source web server
API	Application Programming Interface
BED	University of Bedfordshire, United Kingdom
Cardiorenal disease	the condition characterized by simultaneous kidney and heart disease while the primarily failing organ may be either the heart or the kidney
CC	Creative Commons, a non-profit organization in the field of copyright licensing
Comorbidity	the presence of one or more disorders in addition to a primary disease or disorder (either independently, or as a consequence of the primary condition or otherwise related)
DMOZ	Open Directory Project, a multilingual open content directory of Web links
DUTH	Democritus University of Thrace, Greece
EC	European Commission
EU	European Union
Facebook	On-line social networking service for the general public
FP7	7th Framework Programme for Research and Technological Development, 2007-2013
Google	Web search engine
Google Analytics	A service generating statistics about a website's traffic
ICT	Information and Communication Technologies
KTU	Kaunas University of Technology, Lithuania
LinkedIn	On-line social networking service for professionals
MS ppt	Microsoft Powerpoint commercial presentation editing program by Microsoft®
MySQL	Open-source relational database management system
OU	The Open University, United Kingdom
PHP	Server-side scripting & programming language
PIAP	Industrial Research Institute for Automation and Measurements, Poland
R&D	Research and development
SlideShare	Web 2.0 slide hosting service
STREP	Small or medium-scale focused research project
Twitter	On-line microblogging service
VULSK	Vilnius University Hospital Santariškių Klinikos, Lithuania
Wikipedia	A collaboratively edited, multilingual, free internet encyclopaedia
WordPress	Free and open source blogging tool and content management system
WP	Work programme (as in FP7-WP) or Work package, when related to work within the project

1. Introduction

This document includes the textual presentation of the project, the slide presentation of the project and a short report on the project web presence with links to sites of the project web presence.

Section 2 includes the project facts and textual project presentation, a project press release and the project logo. The project slide presentations (a general purpose presentation and a one-slide presentation) are given in Annex 1 and Annex 2 (and in the respective MS Powerpoint files accompanying this report).

Section 3 includes a short report on the project public web site and project presence in other social media.

2. Project Presentation

2.1. CARRE factsheet

Project identifier	FP7-ICT-2013-611140
Project acronym:	CARRE
Project title:	Personalized patient empowerment and shared decision support for cardiorenal disease and comorbidities
Work programme topic:	ICT-WP-2013.5.1 Personalized health, active ageing, and independent living Target outcome b) Personalised Guidance Services for management of co-morbidities and integrated care
Funding scheme:	Small or medium-scale focused research project (STREP)
Project budget:	3,210,470€
EC funding:	2,573,755€
Duration:	36 months
Start date:	1 November 2013
End date:	31 October 2016
Consortium partners:	1. Democritus University of Thrace (DUTH) – Greece 2. The Open University (OU) – United Kingdom 3. University of Bedfordshire (BED) – United Kingdom 4. Vilnius University Hospital Santariškių Klinikos (VULSK) – Lithuania 5. Kaunas University of Technology (KTU) – Lithuania 6. Industrial Research Institute for Automation and Measurements (PIAP) - Poland
Coordinator contact:	Eleni Kaldoudi Associate Professor Dept. of Medicine Democritus University of Thrace Dragana, Alexandroupoli 68100 Greece Tel.: +30 2551030329 Mob.: +30 6937124358 Email1: kaldoudi@med.duth.gr Email2: carre@med.duth.gr http://www.carre-project.eu/

2.2. CARRE in a nutshell

CARRE is an EU FP7-ICT funded project with the goal to provide innovative means for the management of comorbidities (multiple co-occurring medical conditions), especially in the case of chronic cardiac and renal disease patients or persons with increased risk of such conditions.

Sources of medical and other knowledge will be semantically linked with sensor outputs to provide clinical information personalised to the individual patient, so as to be able to track the progression and interactions of comorbid conditions. Visual analytics will be employed so that patients and clinicians will be able to visualise, understand and interact with this linked knowledge and also take advantage of personalised empowerment services supported by a dedicated decision support system.

The ultimate goal is to provide the means for patients with comorbidities to take an active role in care processes, including self-care and shared decision-making, and also to support medical professionals in understanding and treating comorbidities via an integrative approach (Figure 1).

Figure 1. CARRE puts patient at the center.

2.2.1. Motivation

Comorbidity refers to the presence of one or more disorders in addition to a primary disease or disorder (either independently, or as a consequence of the primary condition or otherwise related). As approximately half of all patients with chronic conditions, even in a nonelderly population, have comorbidities, comorbidity management is a hot topic in current medical literature. When addressing disease in the presence of comorbidities, each different medical condition the patient presents should not be viewed independently, but a “patient as a whole” view approach should be followed. This places an emphasis on and extra burden of dealing successfully with all associations, interactions, co-dependencies, implications, adverse events, etc. that occur between different conditions co-presenting at the same patient at the same time, as well as between the different treatment regimens these conditions involve.

One common case of comorbidities is the chronic cardiorenal disease, which is the condition characterized by simultaneous kidney and heart disease while the primarily failing organ may be either the heart or the kidney. Very often the dysfunction occurs when the failing organ precipitates the failure of the other. The cardiorenal patient (or the person at risk of this condition) presents an interesting case example for addressing and demonstrating novel patient empowerment services for personalized disease & comorbidities management and prevention for a number of reasons as chronic cardiorenal disease has an increasing incidence and a number of serious (and of increasing incidence) comorbidities.

One of the most important aspects of cardiorenal disease and comorbidities diagnosis and treatment is early detection and aggressive management of underlying causes. Preventing progression to end stage renal and cardiac deficiency may improve quality of life and help save health care costs. Prevention of the disease includes: lifestyle modification (controlling obesity, diabetes and hypertension), public-health education for reduction of excessive bodyweight, regular exercise, and dietary approaches, control of hypertension, dietary protein restriction and blood-pressure control, proteinuria management, dyslipidaemia management and smoking cessation. Delaying disease progression is crucial and must include patient education and aggressive treatment and management of chronic cardiorenal disease and its comorbidities. However, effective implementation of such strategies will only come when both the general public and the health care professionals community work together towards public awareness and lifestyle management on a personal basis and following an integrated care approach.

2.2.2. Objectives

CARRE aims to innovate towards a service environment for providing personalized empowerment and shared decision support services for cardiorenal disease comorbidities.

The core of CARRE effort lies in semantic interlinking of three types of data (a) medical ground knowledge (b) up-to-date medical evidence and (c) personal patient data in order to create a personalized model of the disease and comorbidities progression pathways and trajectories (Figure 2). Visual presentations of this personalized model (against ground knowledge and against statistical views of 'similar' patient groups) will form the basis for patient empowerment services that will target understanding of comorbidities in the personal setting. Finally, the personalized model of comorbidities will be used for shared decision support services targeting personalized education, complex risk calculation for disease progression and comorbidity trajectories, alerts for adverse events of multiple co-existing treatments and personalized planning for monitoring.

CARRE aims at creating a dynamic cross referencing of semantically related personalized and evidence based related data.

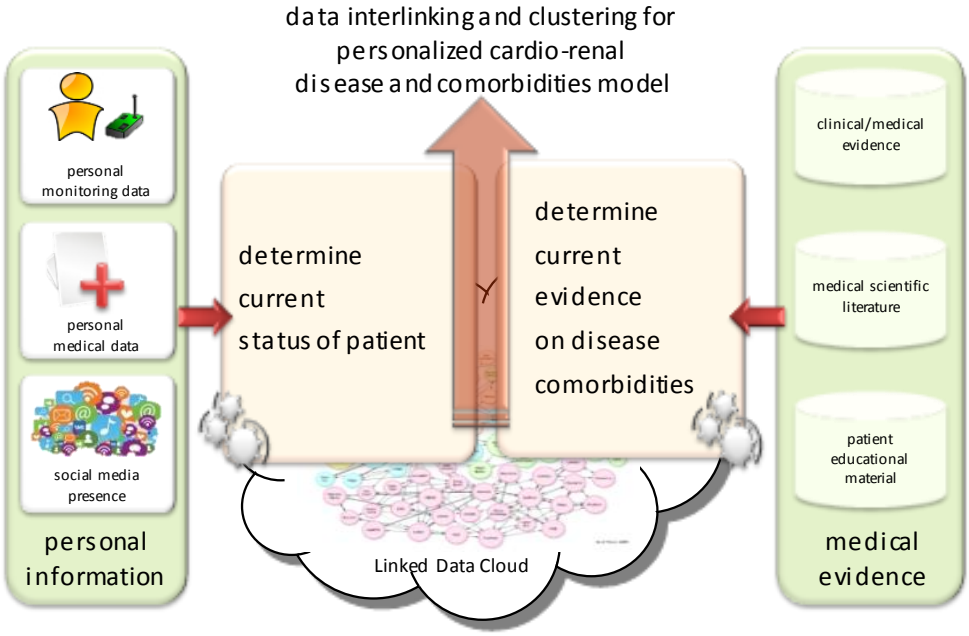


Figure 2. Shifting the focus towards personalized comorbidity management in CARRE.

The overall technological goal of CARRE project is to show the potential of semantic interlinking of heterogeneous data to construct dynamic personalized models of complex comorbid medical conditions with disease progression pathways and comorbidity trajectories. Also, to show that visual analytics based on such models can support patient understanding of personal complex conditions (projected against ground knowledge and statistical views of similar patient population) and be the basis for shared decision support services for the management of comorbidities. In specific the project aims to:

- provide visual and quantitative understanding of disease progression pathways and comorbidities trajectories, as enriched with up-to-date medical evidence and personalized for the individual patient;
- provide personalized risk calculations and analytics for comparison of personal state with the current medical evidence and the overall statistical views of 'similar' patients;
- use the personalized model of comorbidities for building shared decision support services targeting personalized education, complex risk calculation for disease progression and comorbidity trajectories, alerts for adverse events of multiple co-existing treatments and personalized planning for comorbidity monitoring and treatment.

2.2.3. Consortium

In order to achieve the above objectives, CARRE consortium is driven by two partners from the medical domain (University Hospitals), namely **DUTH** and **VULSK** with a clear long experience in medical research in cardiorenal disease and comorbidities as well as with a long record of developing and deploying successful informatics interventions in the real healthcare setting. The core semantic model and interlinking is performed by **OU** a leading expert in semantic technologies, while **BED** undertakes the work on visual analytics and cloud computing – both partners also contribute their long experience in semantic information extraction from unstructured data sources and web service oriented architectures. **KTU,** with a long proven innovation experience in personal sensors and sensor networks for cardiorenal disease tackles the integration of personalized sensor data. Finally, **PIAP** an established partner in security and automation systems brings in the required expertise on decision support systems and on systems security and data privacy.

CARRE consortium partners concise presentation:

No	Acronym	Full Name	Country	Team Leader
1	DUTH	Democritus University of Thrace	Greece	Prof. Eleni Kaldoudi
2	OU	The Open University	United Kingdom	Prof. John Domingue
3	BED	University of Bedfordshire	United Kingdom	Dr. Enjie Liu
4	VULSK	Vilnius University Hospital Santariškių Klinikos	Lithuania	Dr. Domantas Stundys
5	KTU	Kaunas University of Technology	Lithuania	Prof. Arunas Lukosevicius
6	PIAP	Industrial Research Institute for Automation and Measurements	Poland	Prof. Roman Szewczyk

2.2.4. Expected outcomes

The outcomes of the project will be a set of personalised empowerment and shared decision support services as well as respective tools and technologies (Figure 3).

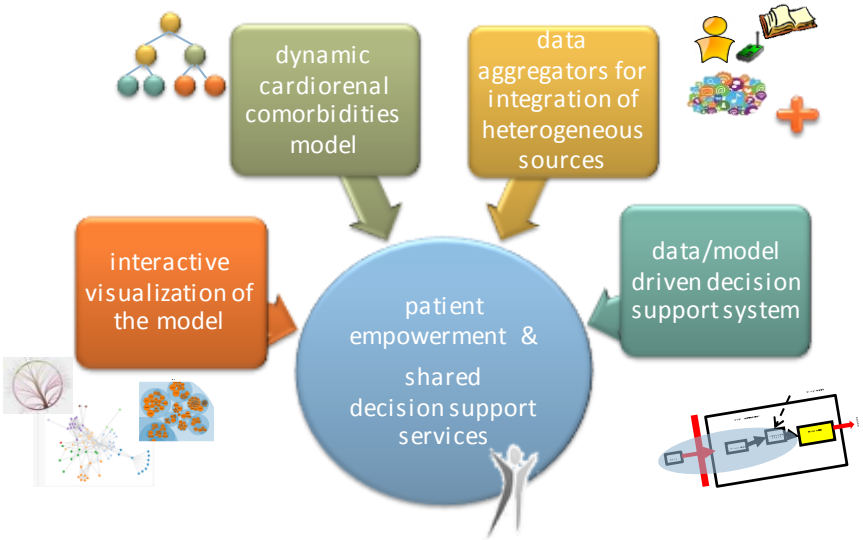


Figure 3. CARRE expected interim and final outcomes.

Major expected technological breakthroughs include:

- an ontology and schema for the description of comorbidities management (in the case of cardiorenal disease and comorbidities);
- data aggregators for integration of heterogeneous sources of information, such as medical evidence, personal data (including dynamic sensor data), medical information and personal disposition & lifestyle;
- text analysis tools to semantically annotate and extract relevant metadata from unstructured sources (medical evidence, social media);
- generic aggregator technology to harvest semantic information from structured data sources as listed above (e.g. personal sensors, educational content items);
- linked data technologies for semantic data interlinking, and enrichment;
- tools and infrastructure for large scale processing of aggregated data for visual analytics mentioned above;
- data/model driven decision support systems to build shared decision support services for the patient and the medical professional based on the personalized comorbidities model of the patient.

2.2.5. Methodology and work plan

The work of CARRE project is organized in 6 technical work packages, complemented by one work package dedicated to project management and one reserved for dissemination and exploitation activities, for a total duration of three years.

Work in each technical work package is led by one consortium partner who commits the main effort based on their expertise, in collaboration with all other partners with complementary expertise required for the various tasks and the smooth integration and cross-fertilization across tasks and WPs.

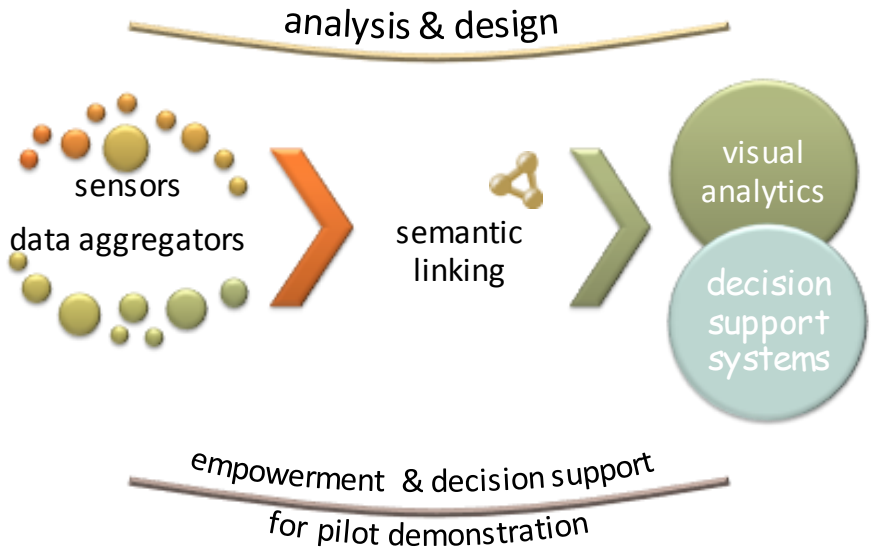


Figure 4.Overview of CARRE technical work plan.

The technical work packages include (Figure 4):

- **Domain analysis, requirements and design**, with activities pertaining to domain analysis, use case definition and design, including the CARRE information model, metadata scheme and ontology, as well as the overall design of the environment;

- **Data and metadata harvesting**, with activities related to harvesting of all heterogeneous data sources related to CARRE – initial task in this WP includes a generic design of the data aggregator for all data sources.
- **Data enrichment, correlation and interlinking**, for the integration, schema mapping and interlinking of the (meta)data provided by the previous work package into a semantic repository;
- **Data management and visual analytics**, with activities pertaining to large-scale graph data management and visualization of the semantic repository and in specific of the personalized comorbidities model for patient empowerment.
- **Empowerment & decision support services**, for the development of personalized shared decision support services; and
- **System integration and evaluation**, for system and service testing and integration, use case deployment and evaluation.

2.2.6. Impact

CARRE project aims to develop an integrated service environment for personalized patient empowerment and shared decision support services for cardiorenal disease and comorbidities. In specific, it aims to:

(a) provide visual and quantitative understanding of disease progression pathways and comorbidities trajectories, as enriched with up-to-date medical evidence and personalized for the individual patient;

(b) provide personalized risk calculations and analytics for comparison of personal state with the current medical evidence and the overall statistical views of 'similar' patients;

(c) use the personalized model of comorbidities for building shared decision support services targeting personalized education, complex risk calculation for disease progression and comorbidity trajectories, alerts for adverse events of multiple co-existing treatments and personalized planning for comorbidity monitoring and treatment.

Specific expected impacts of the project include:

Strengthened quality of life: CARRE aims at strengthening the cardiorenal patient, mainly by reinforcing the patient understanding of the disease and its comorbidities complex interdependencies as they are personalized to the specific patient. Based on this understanding, the project aims to deliver personalized treatment stratification, monitoring alerts and education. CARRE thus implements the "*patients getting up off their knees*" mandate of current patient empowerment initiatives

Reinforced medical knowledge: A recent thorough treatment of comorbidity management suggests that one way to improve care in such cases is to cross reference evidence, knowledge and guidelines for each condition. Simple cross referencing of existing medical evidence and guidelines for all possible combinations of conditions would quickly make it unreadable and thus inefficient. Thus, CARRE follows a personalized and semantically enriched approach to create dynamic cross referencing of related evidence data and medical knowledge with respect to efficient management of cardiorenal comorbidities

Involvement of care authorities in development of personalised care solutions: In contemporary healthcare systems people are usually defined in terms of economic and professional frameworks and are reduced to being mere consumers in need of satisfying, or passive patients in need of treatment or education. In any case, they are not seen as active participants in their own right. CARRE follows an approach of "*first understand, then conquer, then decide*" which targets both the patient and the medical professional. As such it is designed to steer the active involvement of patients and health authorities in the management of comorbidities.

Education for patients and care givers: In order to engage effectively the public (including patients and care givers) ICT technology providers have to somehow address the intellectual gap that usually exists when interventions unavoidably designed and developed by technocrats are offered to be used by the layman. CARRE addresses effectively at least one aspect of this gap, which relates to the often long distance between medical and layman terms involved in the description of disease and treatment plans via semantic coupling either via Linked Data Cloud or dedicated semantic tools.

Improved interaction for patients: Enhancing the patients' and care givers' understanding of the complex interrelations of treatments, adverse events, lifestyle management and disease projections in the case of cardiorenal comorbidities is the basic common ground for understanding each other, and clarifying roles and dispositions, thus enhancing eventually collaboration and participation in the care process.

Improved cooperation between the providers of health: CARRE will provide medical professionals with an overall personalized to the patient visualization of cardiorenal disease and comorbidity projections, as well as with a set of decision support services including comorbidity monitoring planning, alerts for changing plans and alerts of changed risk factor calculation. All these will drive a better and timely communication of the healthcare providers with their peers and the patient caregivers, thus enhancing their collaboration.

2.3. CARRE logo

A strong graphic identity strengthens the project's image, creating a positive and lasting impression and contributes towards an effective communication of the project's main concepts. This is even more important when dissemination addresses the general public. The graphic identity of the project starts with the project logo, which is shown below (Figure 5).

Figure 5. CARRE logo.

The project logo reflects the shape of a kidney artistically reshaped to remind of the shape of half the heart. It also includes the project acronym.

2.4. CARRE slide presentation

A general purpose project slide presentation is given in Annex 2 and in the respective attached MS Powerpoint file.

2.5. CARRE 1-slide presentation

A one-slide project presentation is given in Annex 3 and in the respective attached MS Powerpoint file.

2.6. CARRE press release

EU awards 2,6 million euros to support patient empowerment and shared decision support for the patients that suffer from or are at risk of chronic heart and kidney disease.

To help patients with chronic cardiorenal disease, the European Commission has awarded 2,6 million euros to a collaborative, interdisciplinary research consortium to compile a variety of personalized alerting, planning and educational services so that patients and professionals alike are empowered and can make shared informed decisions.

Cardiorenal syndrome is the condition characterised by simultaneous kidney and heart failure while the primarily failing organ may be either the heart or the kidney. Very often the dysfunction occurs when the failing organ precipitates the failure of the other. Current studies estimate that 9-16% of the overall population is at risk or at the onset of chronic kidney disease, while chronic heart failure amounts to 1-2% of total healthcare costs and end-stage renal disease for more than 2% of total healthcare.

Managing or even preventing this complex but common situation can be challenging as comorbidities require care provision by different medical specialties while addressing a chronic patient trying to lead a normal life. According to Robert Johnstone of the International Alliance of Patient Organizations there is a clear need for “patients to get up off their knees”!

To tackle this problem, the European Commission has decided to fund the CARRE project. This project will use internet aware sensors and other sources of medical information to provide dynamically interlinked clinical information personalized to the patient. Patients and clinicians will be able to visualise, understand and interact with this linked knowledge via a set of decision support service in an all-inclusive and integrated approach the patient with (or at risk of) cardiorenal disease and comorbidities.

The CARRE consortium of 6 partners from 4 countries (Greece, United Kingdom, Lithuania and Poland) is coordinated by the Democritus University of Thrace in Alexandroupoli, Greece. The project is by two partners from the medical domain, namely the Democritus University of Thrace and the Vilnius University Hospital Santariškių Klinikos (LT), with a clear long experience in medical research in cardiorenal disease and comorbidities as well as with a long record of developing and deploying successful informatics interventions in the real healthcare setting. The core semantic model and interlinking is performed by The Open University (UK) a leading expert in semantic technologies, while the University of Bedfordshire (UK) undertakes the work on visual analytics and cloud computing – both partners also contribute their long experience in semantic information extraction from unstructured data sources and web service oriented architectures. Kaunas University of Technology (LT), with a long proven innovation experience in personal sensors and sensor networks for cardiorenal disease tackles the integration of personalized sensor data. Finally, the Industrial Research Institute for Automation and Measurements (PL), an established partner in security and automation systems, brings in the required expertise on decision support systems and on systems security and data privacy.

The overall aim of the CARRE project is to show the potential of semantic interlinking of heterogeneous data to construct dynamic personalized models of complex comorbid medical conditions with disease progression pathways and comorbidity trajectories. Also, to show that visual analytics based on such models can support patient understanding of personal complex conditions (projected against ground knowledge and statistical views of similar patient population) and be the basis for shared decision support services for the management of comorbidities.

All CARRE outcomes will be available as open source, protected under Creative Commons or GNU-GPL and other similar appropriate licensing schemes. CARRE project outcomes will thus be freely available for use and re-use by any interested party. Proof-of-concept will be shown via deployment and evaluation in two different healthcare settings.

The CARRE project is expected to reinforce the cardiorenal patients’ understanding of the disease and the complex interdependencies of existing or projected comorbidities, supporting personalized treatment stratification, monitoring alerts, education and shared informed decision making.

Through these outcomes, CARRE strengthens the EU resolution to put the chronic patient at the centre.

3. Project Web Presence

Project web presence involves of a detailed project web site as well as project presence in a number of popular social media.

3.1. Website

The public part of the web site is available to all web surfers and aims to:

- deliver general information about the project, including acknowledging EU contribution, list of participants, objectives, deliverables, work methodology, dissemination, contact
- inform the public, i.e. patients of cardiorenal disease or at risk of it about the proceedings of the project, and later on act as a portal for accessing CARRE patient empowerment services
- inform health care professionals about the proceedings of the project and later on act as a portal for them to access CARRE decision support services
- act as a unified point of contact and aggregate CARRE web presence.

The web site also includes a private area, which contains all the working documents of the project and as such comprises a live detailed record of the project proceedings. This private web site aims mainly to support communication and collaboration within the consortium and also provide the necessary information to EC project officers and project reviewers. The details of the private web site are presented in CARRE Deliverable "D.1.1. Project communication & coordination infrastructure".

3.1.1. Web domain

The project web domain was chosen to reflect directly the project acronym and identity (i.e. European project). Thus, the project web domain is:

www.carre-project.eu

3.1.2. Implementation

For the official website of the CARRE project the popular open-source platform WordPress[1] was selected. The criteria for the final selection took into consideration various aspects including provisions for customizable code, modular engine supported by a very large community in the forms of plugins and themes, an architecture based on user feedback and discussions and the platform's security.

At the time of original implementation the website used the latest WordPress version (3.7.1) but is constantly updated and maintained keeping up with stable versions. The underlying software infrastructure is a combination of the Apache HTTP server[2], PHP[3] and MySQL[4].

3.1.3. Structure and design

The web site has been designed for 3 different target audience groups and their specific informational requirements:

[1] http://www.wordpress.org
[2] http://apache.org/
[3] http://php.net/
[4] http://www.mysql.com/

- The researcher: as CARRE is a targeted research project, a major target audience is the research community. Informational needs for this group include clear list of all project scientific breakthroughs with links to actual tools, technologies, software etc. that will be developed during the course of the project. Additionally, a major requirement for this audience group is a list and links to scientific publications arising from the project. The audience group of researchers is addressed by the web site area “innovation”.
- The patient or healthy citizen: The major project outcome will be a set of services for patient informed decision making, self-care and empowerment. Informational needs for patients as well as healthy citizens who strive for health empowerment include a clear and simple presentation of the project goal and expected timeline, with regular updates on the proceedings of the project, and finally information on and links to CARRE patient empowerment services. These needs are addressed under project web site area “for the patient”.
- The health care professional: Decision support services for the health care professional are also a major outcome of the project. Informational needs for health care professionals include a professional, scientifically justified description of the project goal and methodology, with regular updates on the proceedings of the project, and finally information on and links to CARRE decision support services. These needs are addressed under project web site area “for the professional”.

Additional information required for all audience groups is the comprehensive presentation of the project itself, acknowledging EU contribution, and including information on project consortium, external advisory boards, goal and work plan strategy, as well as links to public project deliverables. These needs are addressed under the project web site area “the project”.

The navigation of the web site is organized to a maximum of three levels. The overall structure consists of 4 main regions:

- Project: information on the CARRE project;
- Innovation: addressing the researcher with information and links for downloading project publications and technological outcomes (e.g. source code, software, tools and services);
- For the patient: addressing the patient with info on cardiorenal disease and the expected project outcomes – this area will be fully deployed later in 2014 as the first results of the project will be available;
- For the professional: addressing the healthcare professional with info on latest medical evidence for cardiorenal disease management and project outcomes - this area will be fully deployed later in 2014 as the first results of the project will be available.

Additionally, there are links to an interactive calendar for project related events, project contacts and the private members’ website (for project collaboration, see D.1.1)

The sitemap including the 1st and 2nd link levels is shown in Figure 6 while the overall structure of the pages is shown in Figure 7.

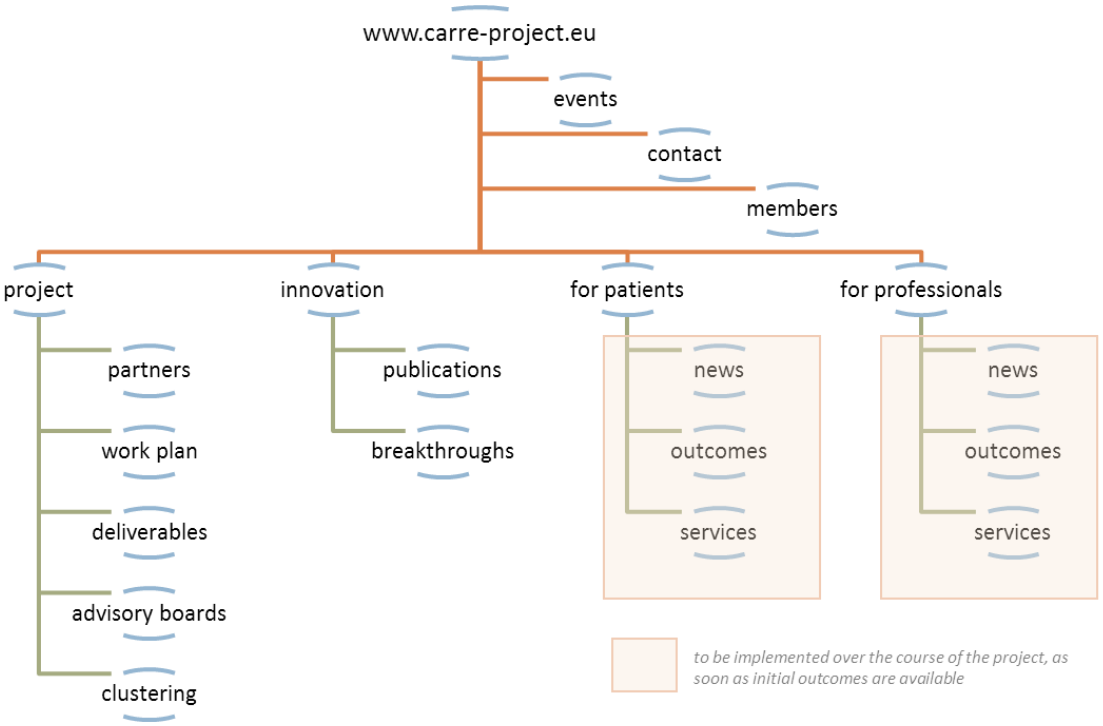


Figure 6. CARRE public website map.

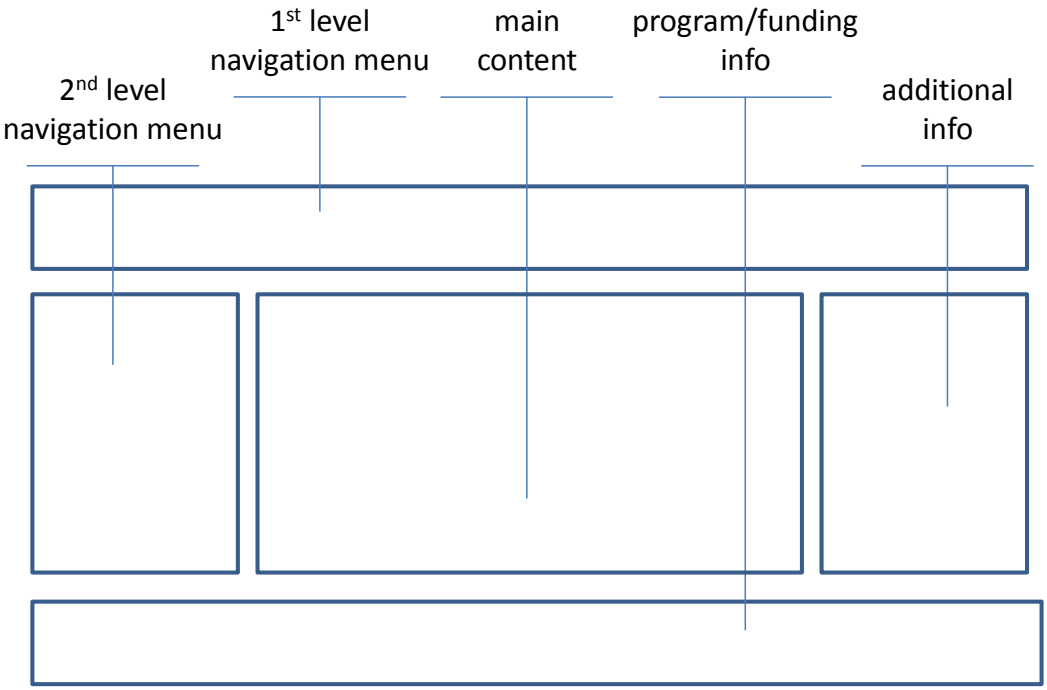


Figure 7. CARRE web page overall structure.

3.1.4. Web site promotion & analytics

The project web site is promoted by

- free submission to internet directories (e.g. DMOZ[5]) or to search engines (e.g. Google[6]).
- addition of links or references on CARRE partners' websites.
- inclusion of reciprocal links or references with websites of related initiatives and R&D projects (deployment over the course of the project along with clustering activities and associated partners activities).
- project's dissemination material, such as brochures, presentations, press-releases, where the website URL must be highlighted.

The CARRE website implements the Google Analytics API in order to keep track of site usage and other analytics like demographic information. These statistics will be made available during progress reports and on demand.

3.2. Social media

The project's web presence is complemented with pages in a number of general purpose popular social media, as described below.

A Twitter account was set for the project at https://twitter.com/CARREproject, Twitter handle: @CARREproject (Figure 8). This is intended for a quick and easy dissemination of all project news as well as for re-tweeting news published by related projects and organizations, e.g. EU_Health etc. A feed of the Twitter account is also shown on the front page of the CARRE website.

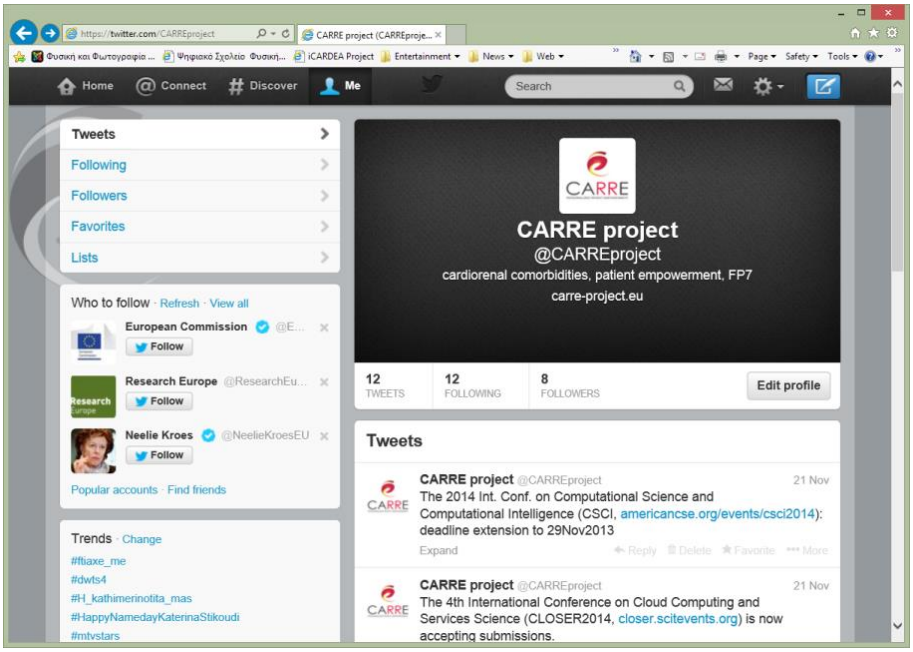


Figure 8. Screen dump of the CARRE Twitter account page.

[5] Open Directory Project (DMOZ). "Homepage". http://www.dmoz.org/
[6] Google. "Addurl". http://www.google.com/addurl/?continue=/addurl

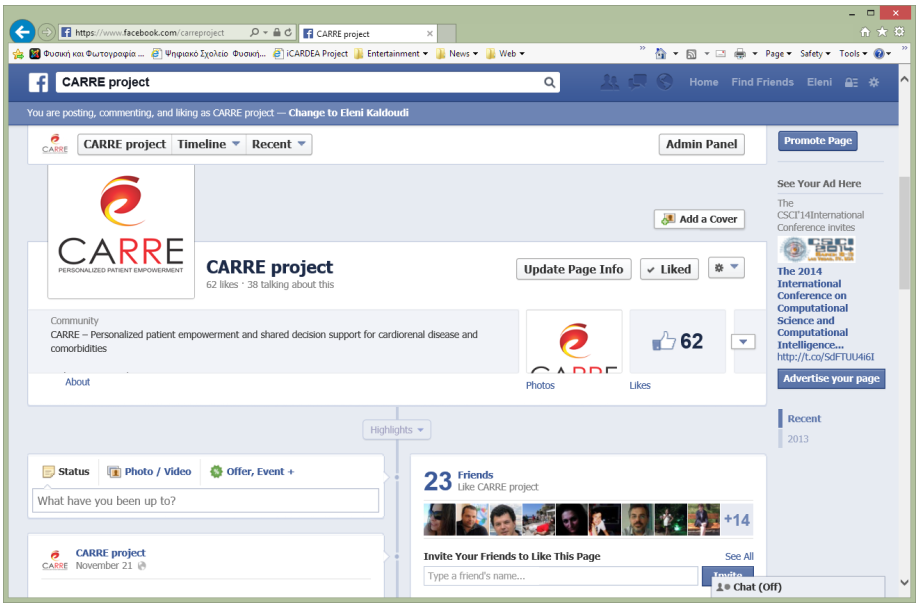


Figure 9. Screen dump of the CARRE page on Facebook.

A Facebook page was also set up for CARRE project at https://www.facebook.com/carreproject (Figure 9). Taking into consideration the wide penetration of Facebook in the international community, the CARRE page on Facebook is intended for disseminating news and outcomes of the project, mainly for public.

To address professionals (both ICT research and medical experts), a CARRE group page has been set up on LinkedIn at http://www.linkedin.com/groups/CARRE-project-7414888?trk=my_groups-b-grp-v (Figure 10).

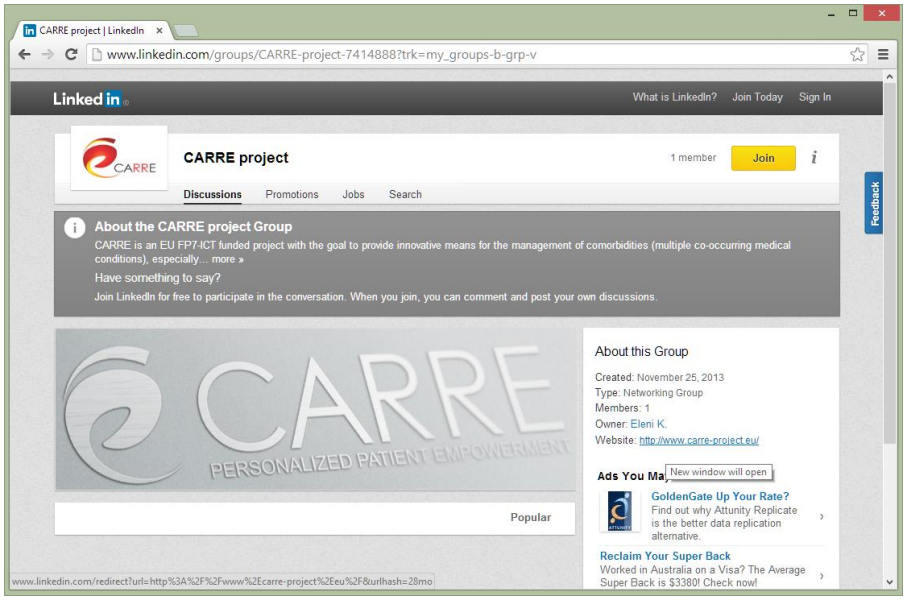


Figure 10. Screen dump of the CARRE Group page on LinkedIn.

A SlideShare account for CARRE project was set up at http://www.slideshare.net/carre-project (Figure 11). This is intended for wider and seamless dissemination of project related presentations. The default copyright license is set to CC Attribution-NonCommercial-ShareAlike.

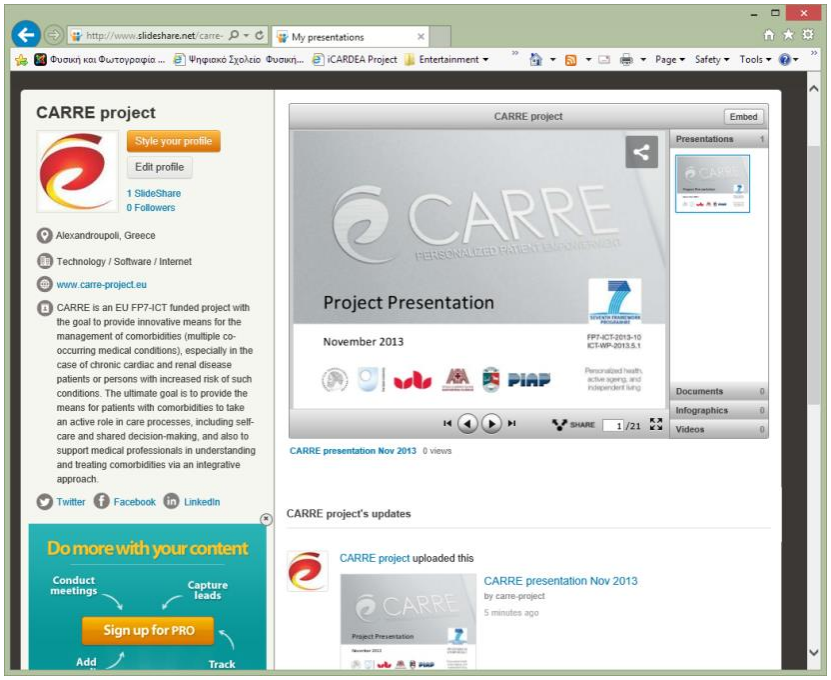


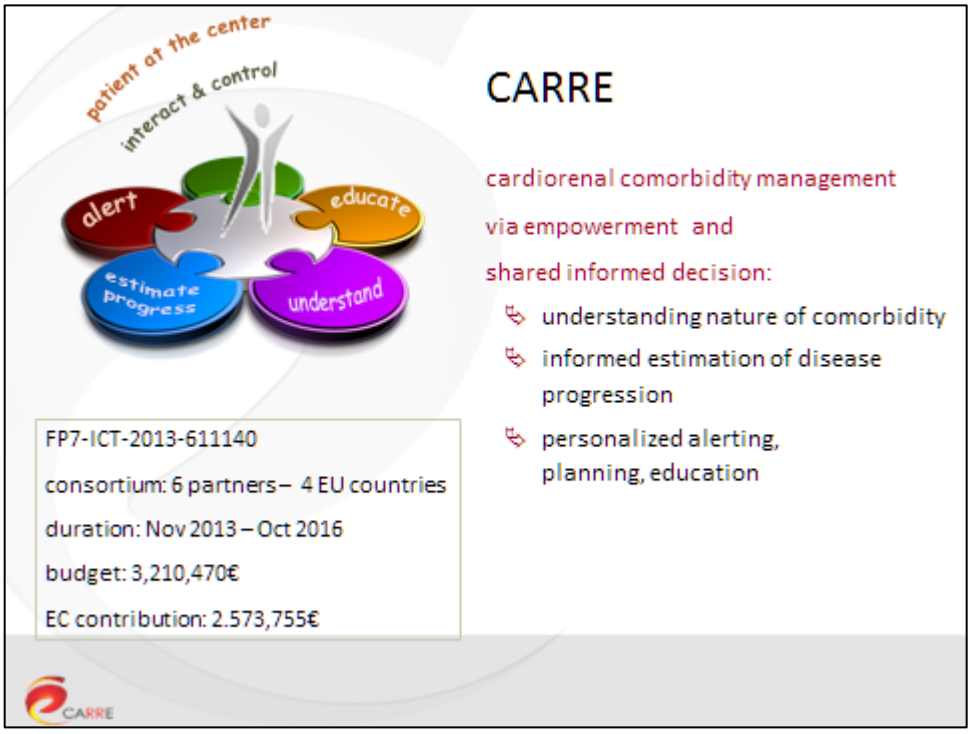
Figure 11. Screen dump of the CARRE account on SlideShare.

Finally, the project will eventually be presented on Wikipedia. However, the first attempt towards an encyclopaedia entry did not meet the Wikipedia criteria and the page was not retained (deemed to only promote the project and not of encyclopaedic relevance). It is expected that the page will be of encyclopaedic relevance when first results (e.g. domain analysis and information model, ontology, etc.) will be ready for dissemination (by the end of the project's 1st year).

Annex 1

Project Presentation Slides


CARRE
PERSONALIZED PATIENT EMPOWERMENT
Project Presentation
SEVENTH FRAMEWORK PROGRAMME
November 2013
FP7-ICT-2013-10
ICT-WP-2013.5.1
PIAP
Personalized health, active ageing, and independent living


patient at the center
interact & control
alert
educate
estimate progress
understand
CARRE
cardiorenal comorbidity management
via empowerment and
shared informed decision:
understanding nature of comorbidity
informed estimation of disease progression
personalized alerting, planning, education
FP7-ICT-2013-611140
consortium: 6 partners– 4 EU countries
duration: Nov 2013 – Oct 2016
budget: 3,210,470€
EC contribution: 2.573,755€
CARRE

motivation

facts:

- ½ of all chronic patients present comorbidities
- only a few overall management guidelines exist
- patients receive fragmented, disease specific care

current research on comorbidities management suggests that improved management of comorbid patients may result via:

- educational and empowering interventions
- shared decision support

medical domain

chronic cardiorenal disease and comorbidities

- simultaneous (causal) dysfunction of kidney and heart
- diabetes and/or hypertension common underlying causes
- a number of other serious comorbidities often present

  nephrogenic anemia, renal osteodystrophy, malnutrition, blindness, neuropathy, severe atherosclerosis, cardiovascular episodes, and eventually end-stage renal disease and/or heart failure, and death

- deterioration to end stage renal/heart disease is life threatening, irreversible and expensive to manage

cardiorenal disease & comorbidities

some numbers…

- hypertension ⇨ 1/3 of adults (US 2008)
- diabetes ⇨ 8% of overall population
- chronic kidney disease ⇨ 9-16% of overall population
- 44% of chronic kidney disease is due to diabetes
- 86% of chronic kidney disease has at least 1 comorbidity
- most patients with chronic kidney disease develop cardiovascular disease

➤ chronic heart failure ⇨ 1-2% of total healthcare costs

➤ end-stage renal disease (dialysis) ⇨ >2% of total healthcare costs

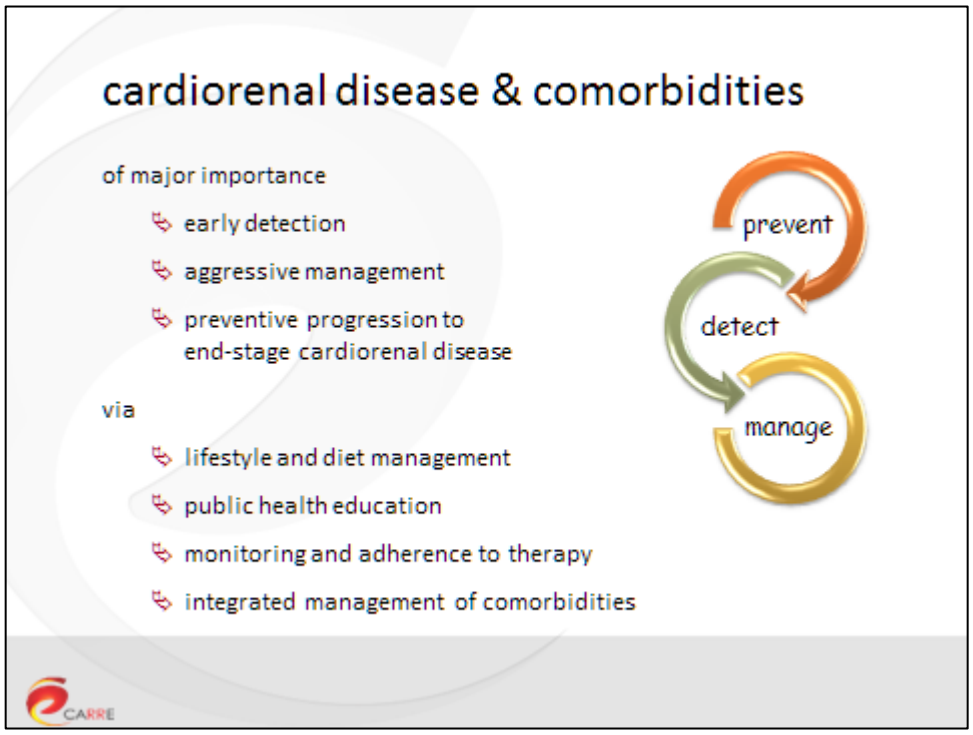
Dr. D. O' Donoghue,
UK's National Clinical Director for Kidney Care (2008):

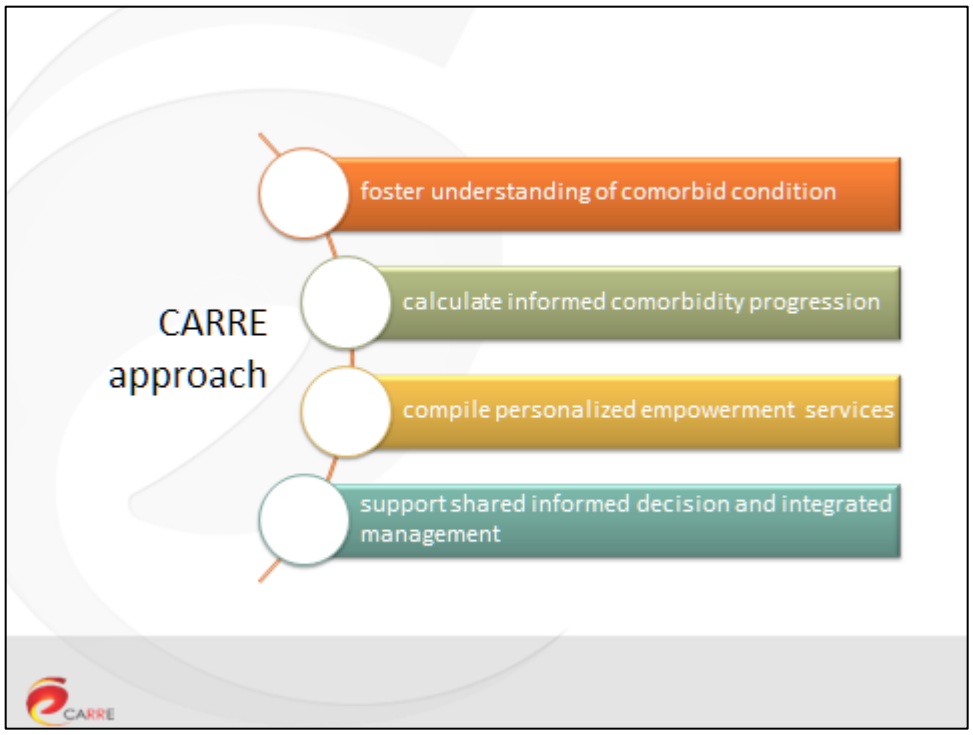
"We can count the cost of kidney disease in financial terms, but the impact on the lives of patients as a result of late identification and diagnosis is incalculable.

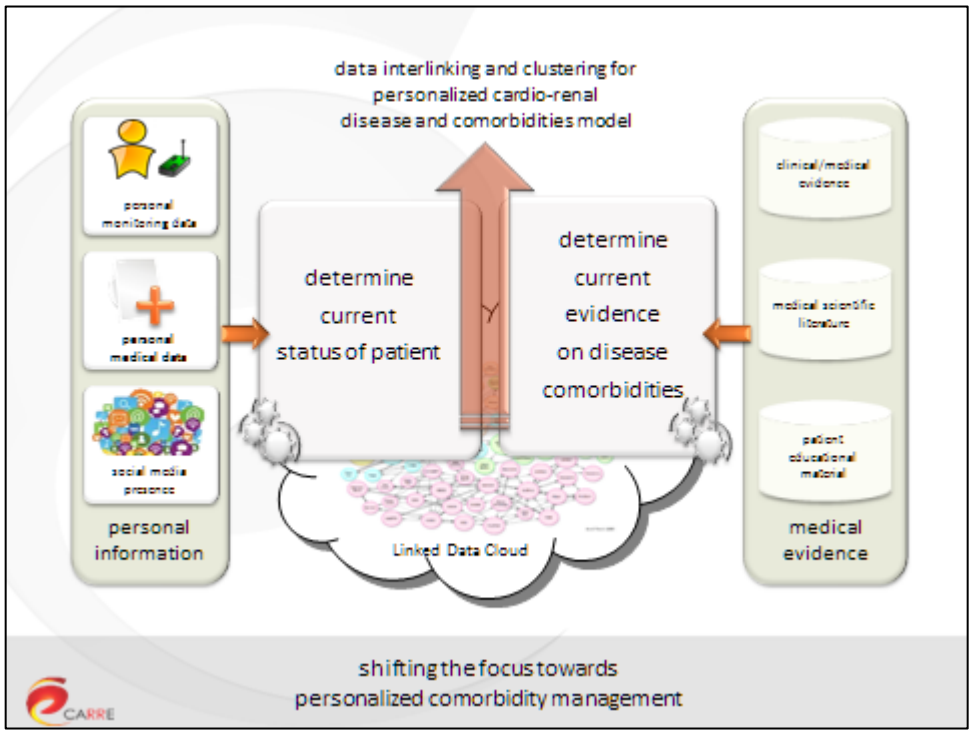
In the UK, dialysis alone accounts for 2% of the total NHS budget (=150 billion €) and this is projected to double over the next five years.

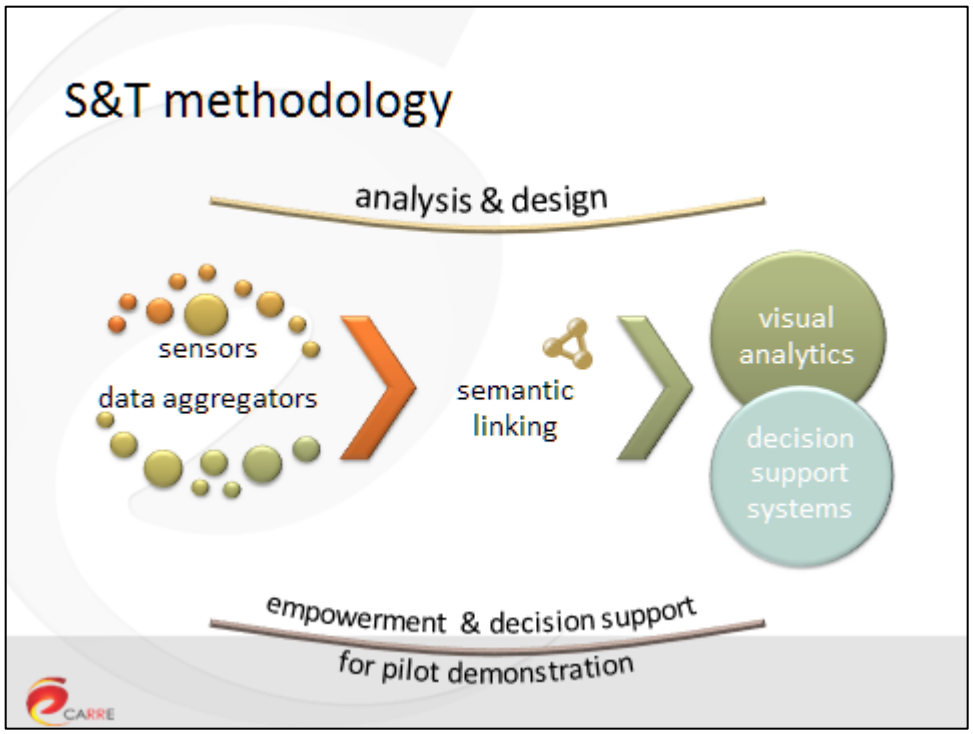
In comparison, the cost of implementing CKD prevention strategies can be modest".

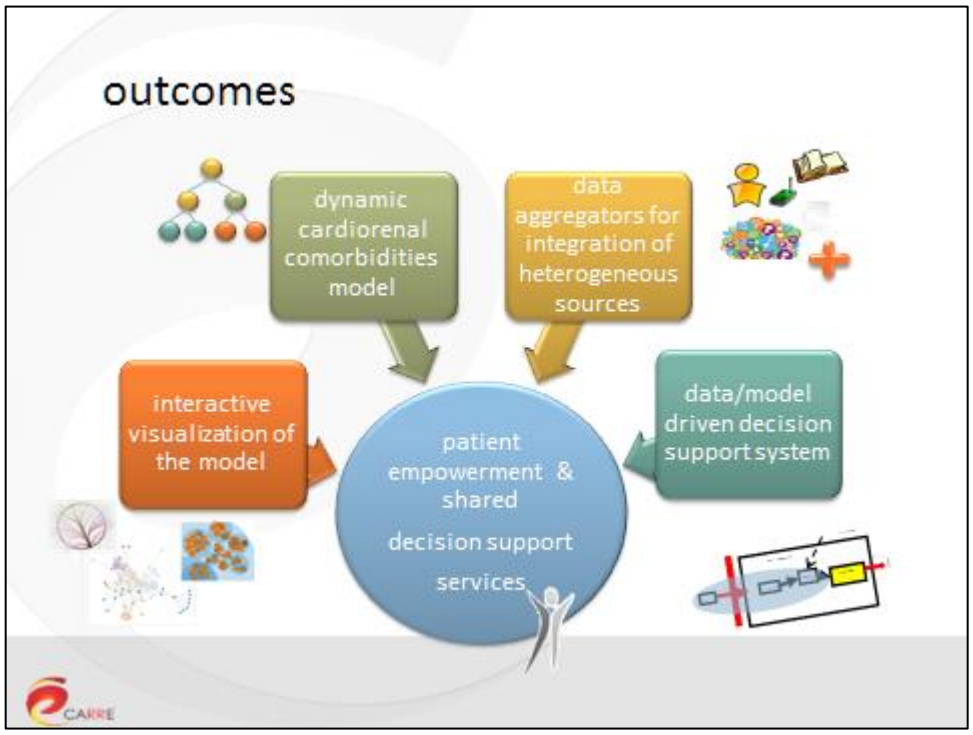
http://www.medicalnewstoday.com/releases/99428.php


cardiorenal disease & comorbidities
of major importance
early detection
aggressive management
preventive progression to end-stage cardiorenal disease
via
lifestyle and diet management
public health education
monitoring and adherence to therapy
integrated management of comorbidities
prevent
detect
manage


CARRE approach
foster understanding of comorbid condition
calculate informed comorbidity progression
compile personalized empowerment services
support shared informed decision and integrated management


data interlinking and clustering for personalized cardio-renal disease and comorbidities model
personal monitoring data
personal medical data
social media presence
personal information
determine current status of patient
determine current evidence on disease comorbidities
Linked Data Cloud
clinical/medical evidence
medical scientific literature
patient educational material
medical evidence
shifting the focus towards personalized comorbidity management


S&T methodology
analysis & design
sensors
data aggregators
semantic linking
visual analytics
decision support systems
empowerment & decision support
for pilot demonstration



work plan

1st year: **analysis and modeling**
analysis, design, model & ontology,
initialization of RTD tools design and development

2nd year: **main technological research and development**
data harvesting, model/RDF population,
system visual interface, DSS infrastructure
testing

3rd year: **enhancements, deployment & validation**
advanced analytics, integrated services, pilots,
evaluation, implications

⇨ strong user involvement in all phases of RTD
⇨ a clear task-deliverable correspondence

milestones

1st year

M03 ⇨ MS1: project successfully initiated

M12 ⇨ MS2: a comprehensive CARRE information model has been developed – 1st draft of RDF ready

2nd year

M14 ⇨ MS3: a working CARRE RDF scheme and ontology have been produced

M18 ⇨ MS4: data aggregators are efficiently working

M24 ⇨ MS5: visual interface to the RDF store is completed

3rd year

M30 ⇨ MS6: service environment integration has produced a first working prototype

M36 ⇨ MS7: project successfully completed

disseminate & exploit

main focus during
the entire lifetime
of the project and beyond
(not just in the end!!)

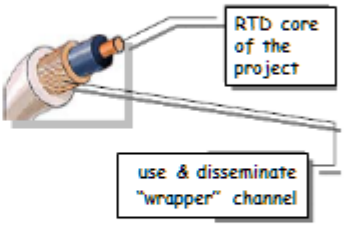
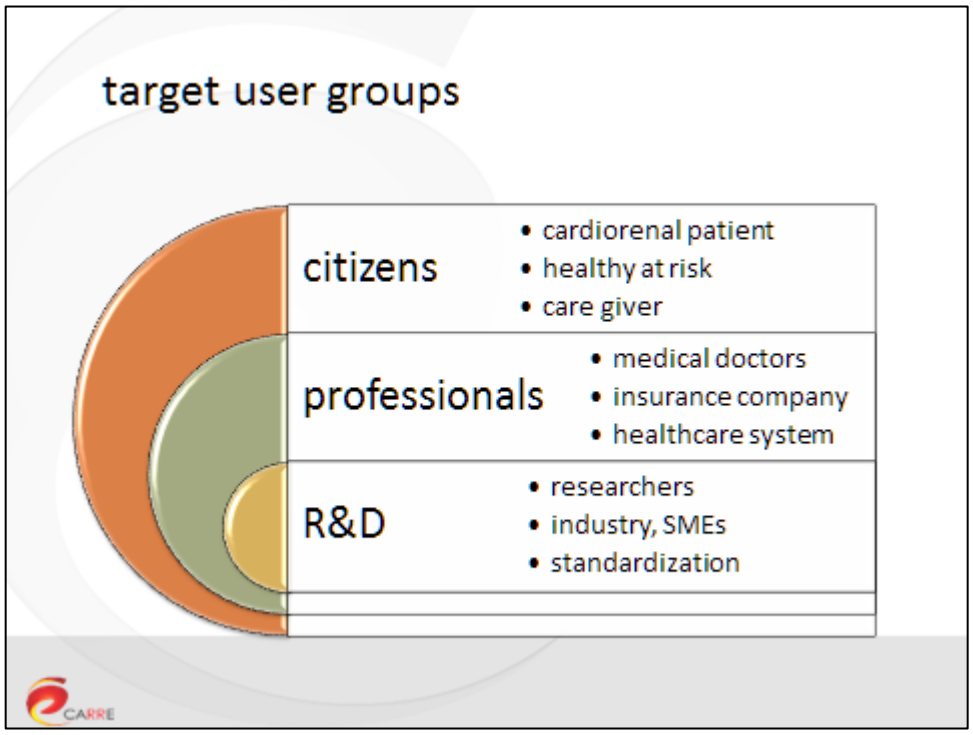
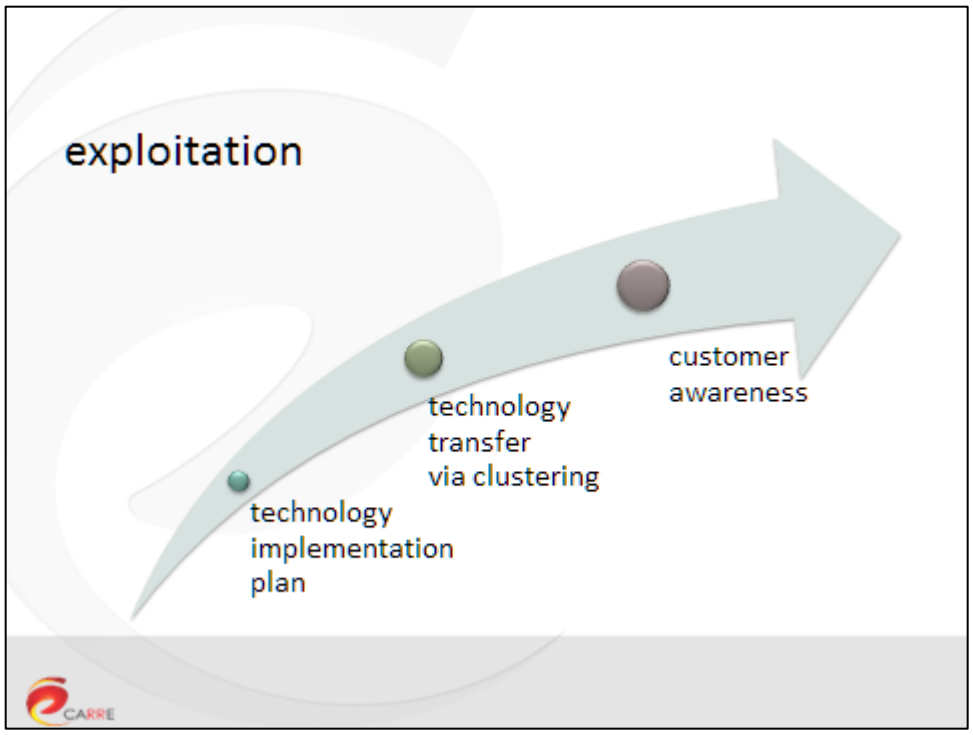
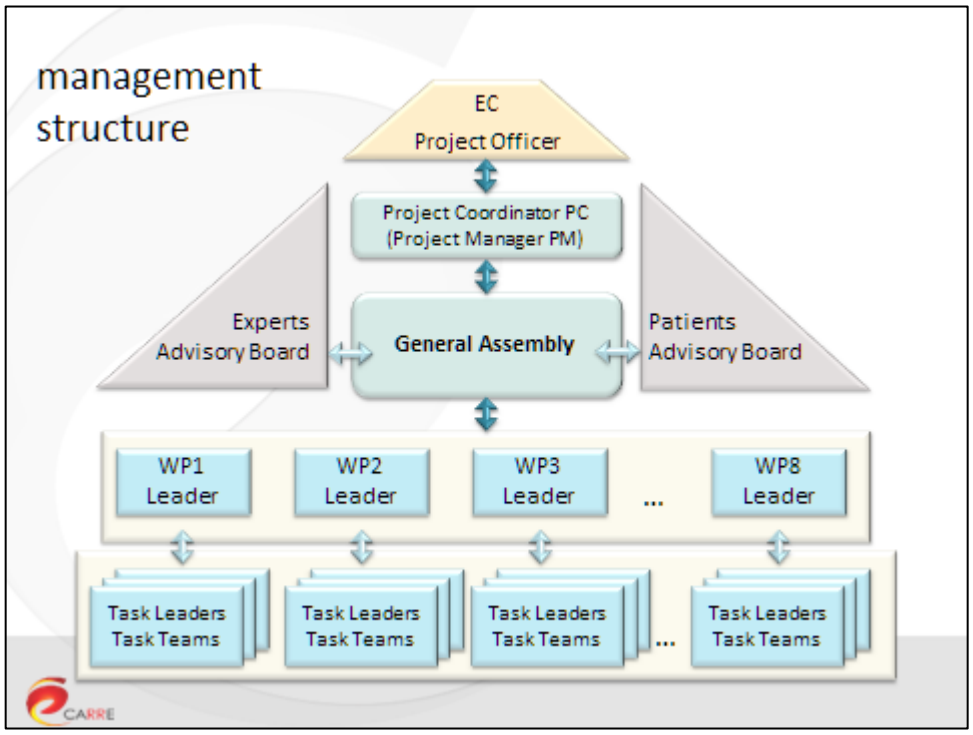
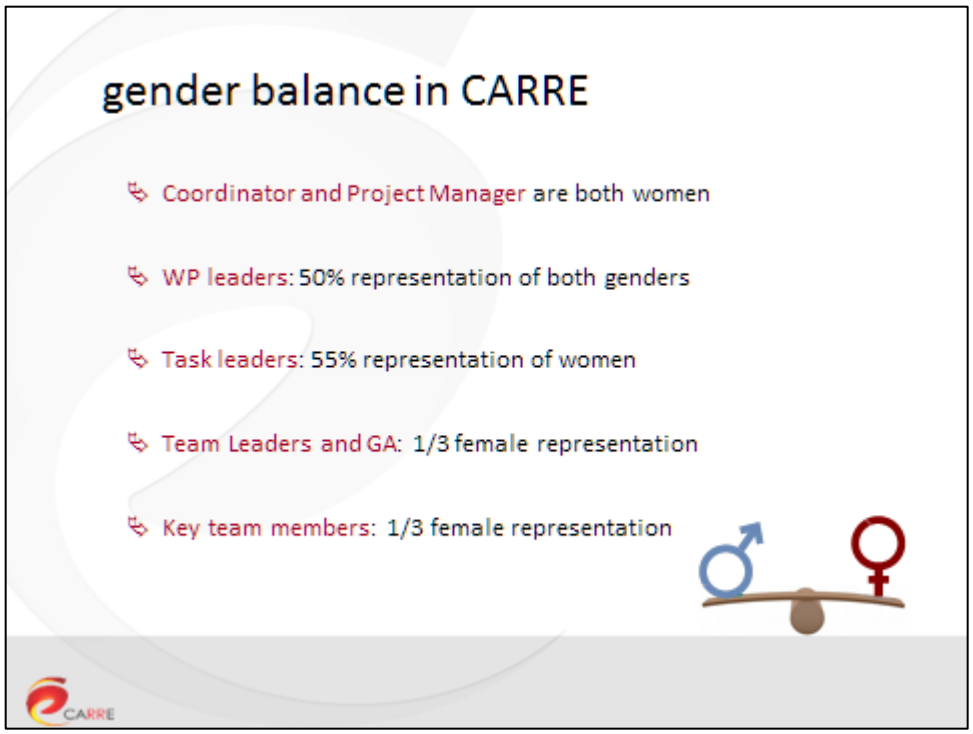


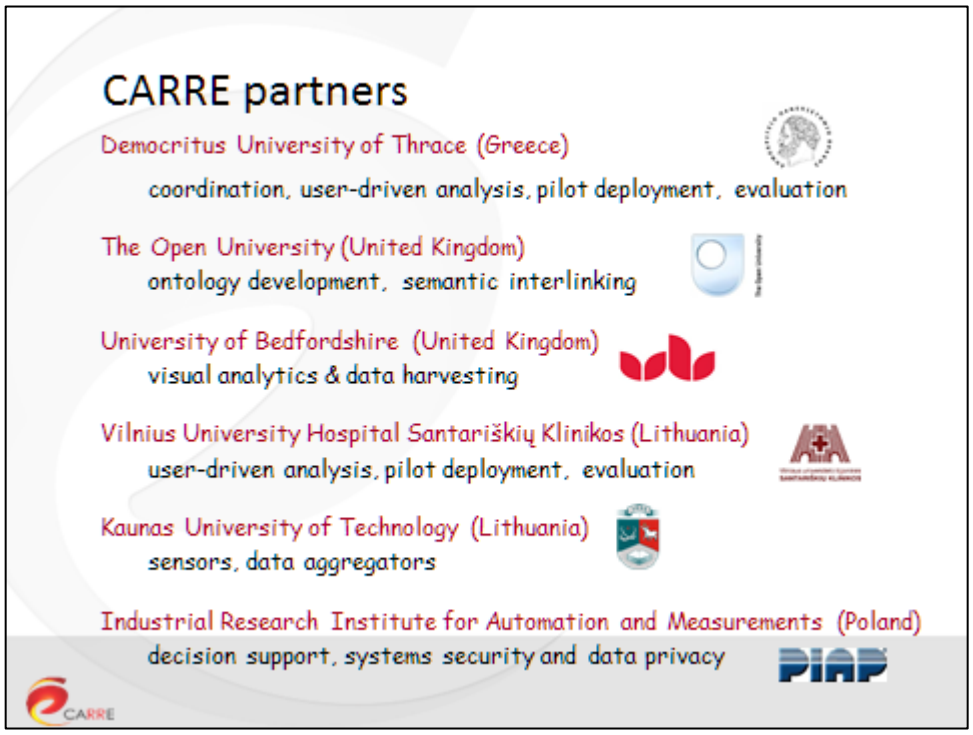
Figure adapted from: SCUBE-ICT, HAGRID, and IST_BONUS project consortia, "Training Guide: Getting Started with EU ICT Research, SCUBE-ICT, EU, September 2009 (p. 45)


target user groups
citizens
• cardiorenal patient
• healthy at risk
• care giver
professionals
• medical doctors
• insurance company
• healthcare system
R&D
• researchers
• industry, SMEs
• standardization


exploitation
technology implementation plan
technology transfer via clustering
customer awareness


management structure
EC
Project Officer
Project Coordinator PC
(Project Manager PM)
Experts
Advisory Board
General Assembly
Patients
Advisory Board
WP1
Leader
WP2
Leader
WP3
Leader
...
WP8
Leader
Task Leaders
Task Teams
Task Leaders
Task Teams
Task Leaders
Task Teams
...
Task Leaders
Task Teams


gender balance in CARRE
Coordinator and Project Manager are both women
WP leaders: 50% representation of both genders
Task leaders: 55% representation of women
Team Leaders and GA: 1/3 female representation
Key team members: 1/3 female representation


CARRE partners
Democritus University of Thrace (Greece)
coordination, user-driven analysis, pilot deployment, evaluation
The Open University (United Kingdom)
ontology development, semantic interlinking
University of Bedfordshire (United Kingdom)
visual analytics & data harvesting
Vilnius University Hospital Santariškių Klinikos (Lithuania)
user-driven analysis, pilot deployment, evaluation
Kaunas University of Technology (Lithuania)
sensors, data aggregators
Industrial Research Institute for Automation and Measurements (Poland)
decision support, systems security and data privacy
PIAP
CARRE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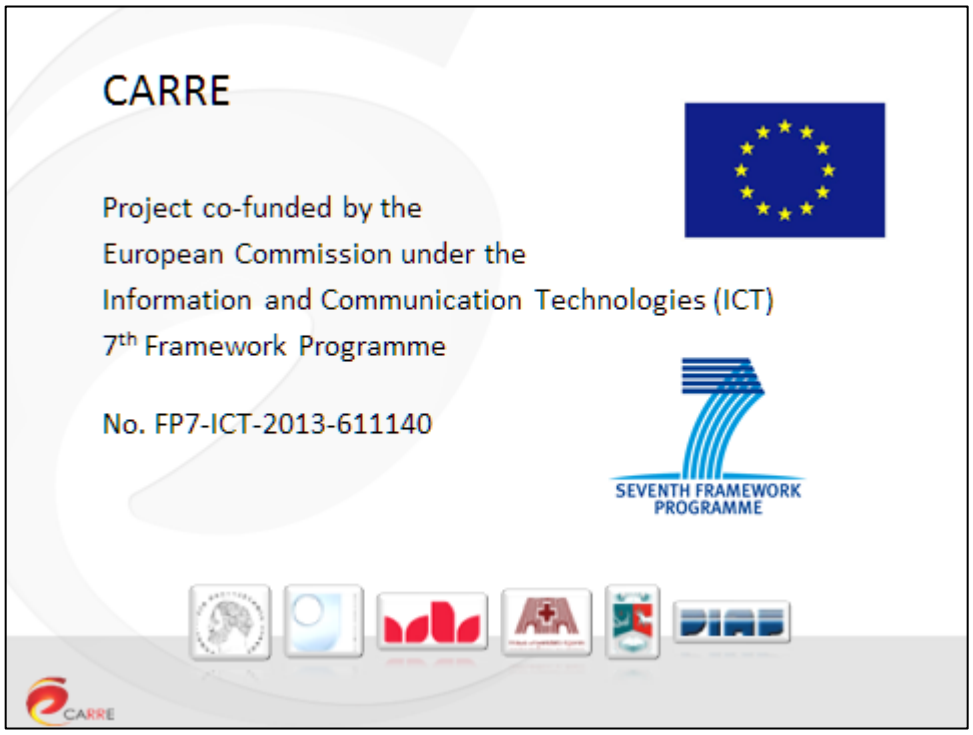
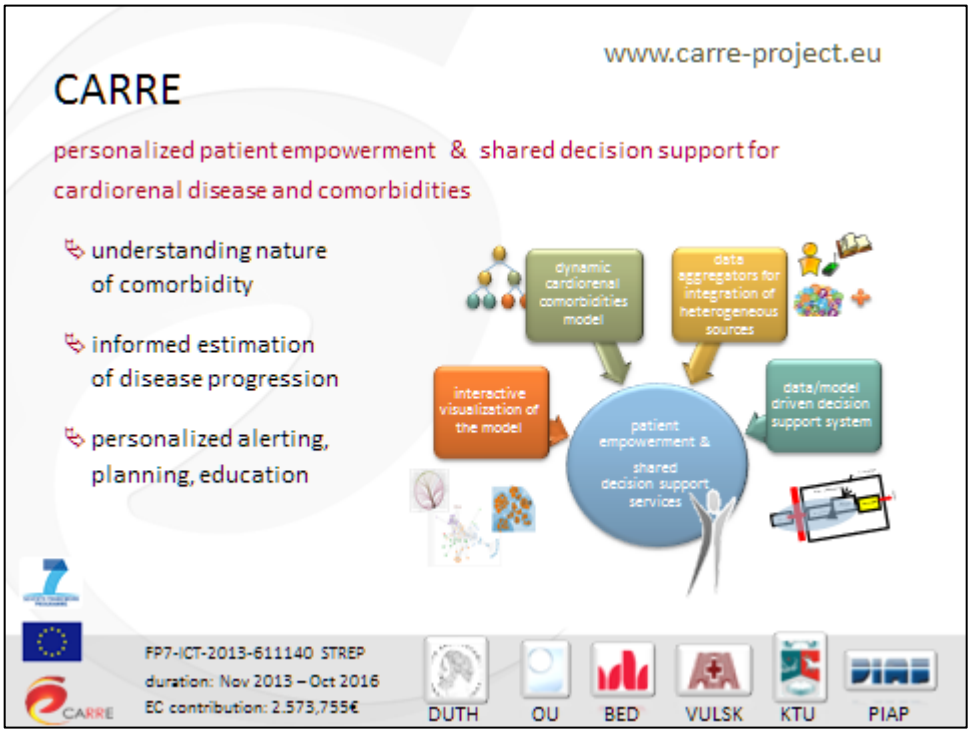
KTU Arunas Lukosevicius arunas.lukosevicius@ktu.lt
PIAP Roman Szewczyk rszewczyk@piap.pl
CARRE


CARRE
Project co-funded by the
European Commission under the
Information and Communication Technologies (ICT)
7th Framework Programme
No. FP7-ICT-2013-611140
SEVENTH FRAMEWORK
PROGRAMME
CARRE

Annex 2

1-Slide Project Presentation


www.carre-project.eu
CARRE
personalized patient empowerment & shared decision support for cardiorenal disease and comorbidities
understanding nature of comorbidity
informed estimation of disease progression
personalized alerting, planning, education
dynamic cardiorenal comorbidities model
data aggregators for integration of heterogeneous sources
interactive visualization of the model
patient empowerment & shared decision support services
data/model driven decision support system
FP7-ICT-2013-611140 STREP
duration: Nov 2013 – Oct 2016
EC contribution: 2.573,755€
DUTH
OU
BED
VULSK
KTU
PIAP