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PROJECT PERIODIC REPORT

PART 2: Publishable Summary

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Disclaimer

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Publishable Summary

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.

Motivation and objectives

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 have comorbidities, their 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 co-presenting conditions.

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.

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. 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.

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 2).

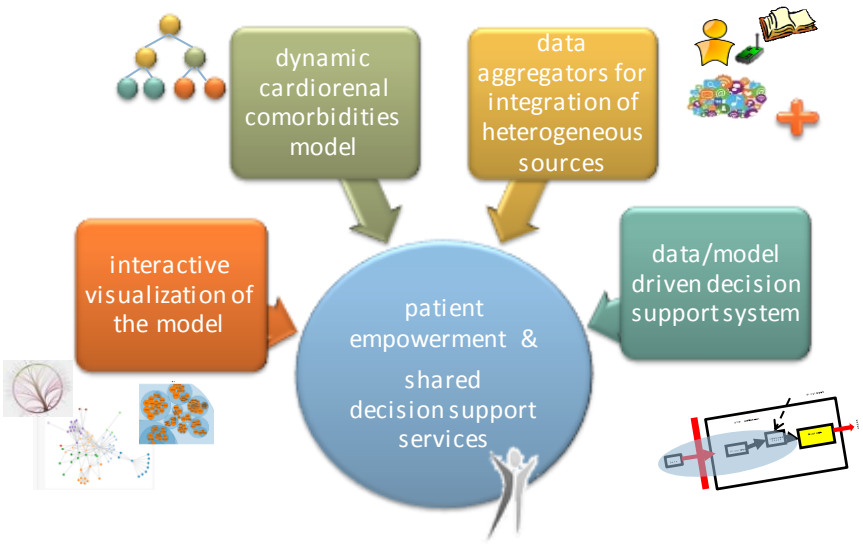

Figure 2. CARRE expected interim and final outcomes.

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);
- 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.

Significant results achieved so far

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. The project work plan is structured in three consecutive phases (Figure 3):

1st year: analysis and modeling;

2nd year: main technological research and development; and

3rd year: enhancements, deployment & validation.

Significant achievements during the first two years are described below.

Literature review of the medical domain revealed that cardiorenal disease and comorbidities is a complex domain. Related conditions do not have a single cause, but evidence suggests that there are multiple causal chains. In order to capture this in CARRE, current evidence is presented as a complex network of risk factors, i.e. pairs of conditions one related to another via a causal relationship. Thus, we have developed a conceptual model to describe risk factors in medicine and subsequently created the corresponding ontology, also published in NCBO Bioportal (http://bioportal.bioontology.org/ontologies/CARRE).

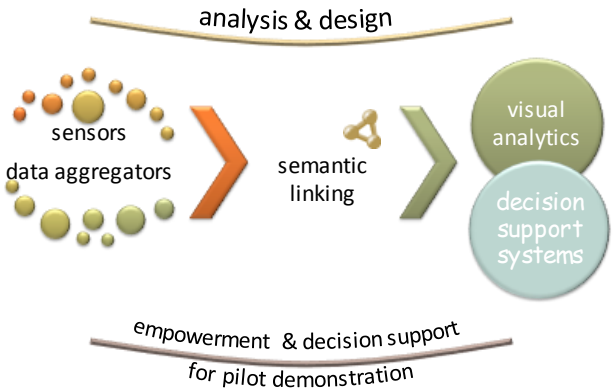

Figure 3. Overview of CARRE technical work plan.

We have also developed an application to facilitate medical experts to use the CARRE model in order to enter descriptions of risk factors in a publicly available repository. The aim is to create a first draft of a database (as a 'seed' risk factor database) to showcase that the risk factor model and ontology works and to support CARRE DSS. The on-line system for browsing the risk factor repository is available at http://entry.carre-project.eu). The repository currently includes description for 98 risk factors related to cardiorenal syndrome and comorbidities, which correspond to 253 different risk evidences as identified by 60 different evidence sources. These involve 53 risk elements and 63 observables. Figure 4 shows a typical screen shot of the risk factor description system displaying the list of risk evidences as well as the detailed description of a particular risk evidence.

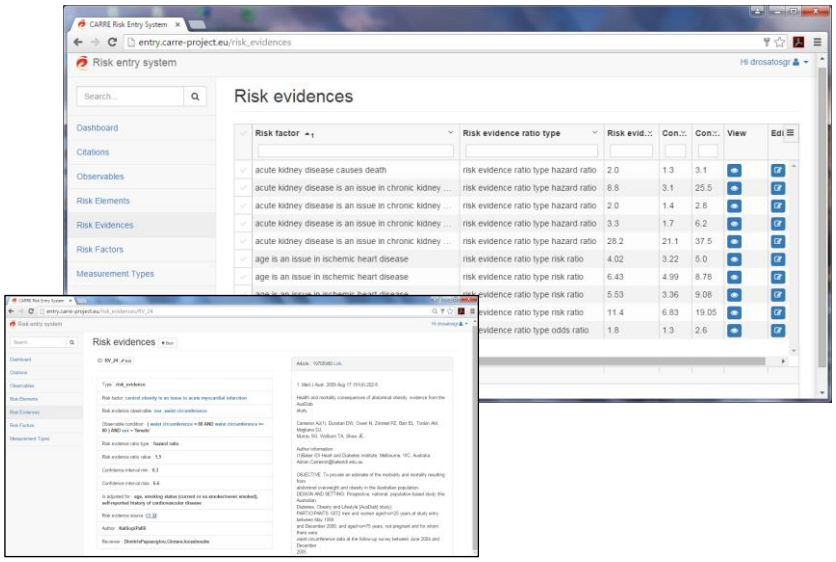

Figure 4. The list of risk factors with their different risk evidences. A particular risk evidence with all its information. On the right part of the screen the evidence source from PubMed is dynamically uploaded (bottom left).

The risk factor database will be updated continually based on state-of-the-art scientific publications. To facilitate this process, we have initiated the development of novel semantic analysis tools of scientific literature databases (PubMed) that will allow semi-automatic extraction of information on possible risk factors from published works.

We have also conducted critical analysis of available 3rd party personal sensors and other sources of information including personal health record systems and educational repositories for patients. The development of aggregators for all these types of external data has been concluded. The integrated personal data aggregators can be accessed at https://carre.kmi.open.ac.uk/devices/ (Figure 5).

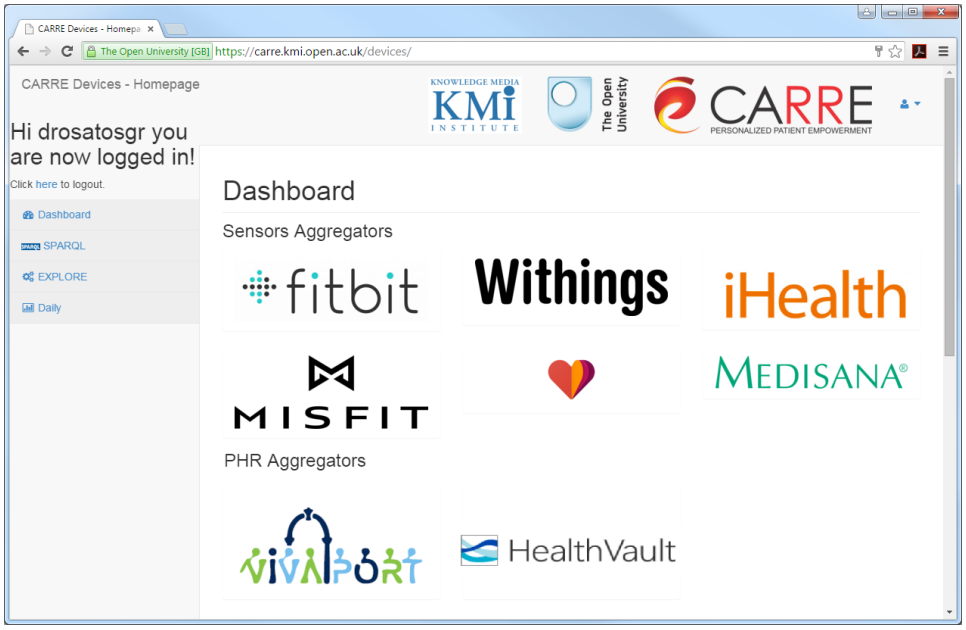

Figure 5. Personal aggregators integration portal at https://carre.kmi.open.ac.uk/devices/

The core of the system is the RDF repositories, holding personal and public data. These are implemented using the open-source Virtuoso database[1], which provides a highly scalable RDF triplestore (instances of Virtuoso are capable of handling, e.g., 15.4 billion RDF triples[2]) supporting a comprehensive range of RDF formats and efficient querying. A single-sign on authentication mechanism has been implemented using the standard OAuth2[3] architecture: users may sign in to any CARRE application and thereby be securely signed on to all CARRE applications and able to access everything to which they have permission. A high-level web-based API has been developed to allow CARRE applications easy execution of common tasks with public and private RDF data. The API is extensible and allows performance tuning of the repository without affecting application quality.

CARRE system is intended as a personal ehealth systems to be used by the citizens themselves to acquire, store, and manage personal health data and use these for empowerment and shared decision support. Therefore, ensuring data privacy is of paramount importance. To this extend, the consortium conducts research towards a best-practices methodology for privacy by design in personal ehealth systems. Initial results of this work is an analysis and a model of the major functionalities of personal ehealth systems in view of their data privacy requirements. Based on the requirements for personal data communication in a personal e-Health system (Figure 6), the following basic personal e-health systems functionalities can be identified (Figure 7): (1) personal data storage and processing; (2) personal data exchange with other third party systems (personal or institutional); (3) integration of (personalized) public data; (4) exporting personal data for public (e.g. statistical) use; and (5) exchange of private personal data messages. Work in progress involves the development of a best practices methodology for privacy by design personal ehealth systems which then will be demonstrated in the example of CARRE project.

1 http://virtuoso.openlinksw.com

2 http://www.w3.org/wiki/LargeTripleStores#OpenLink_Virtuoso_v6.1_-_15.4B.2B_explicit.3B_uncounted_virtual.2Finferred

3 http://oauth.net/2/

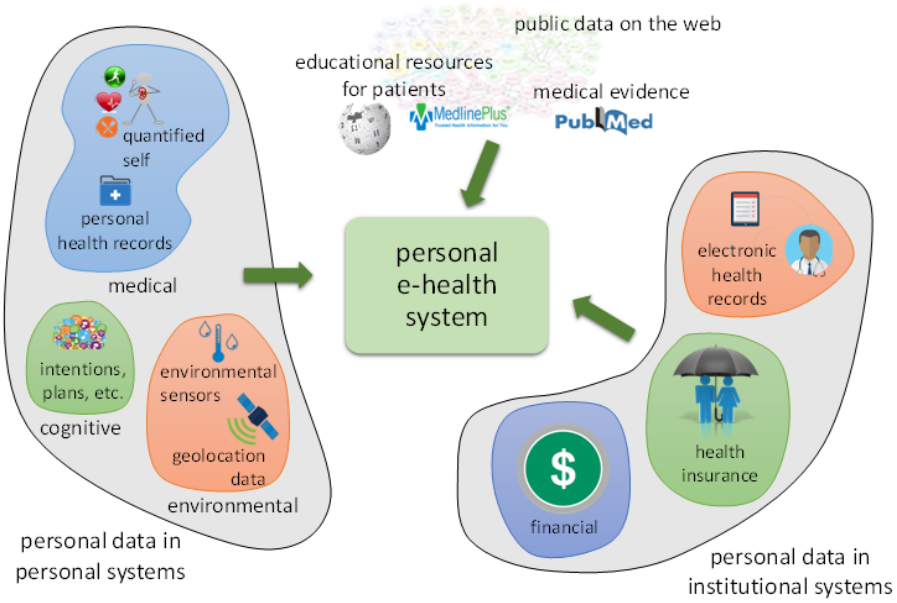

Figure 6. Data communication requirements in a personal e-health system

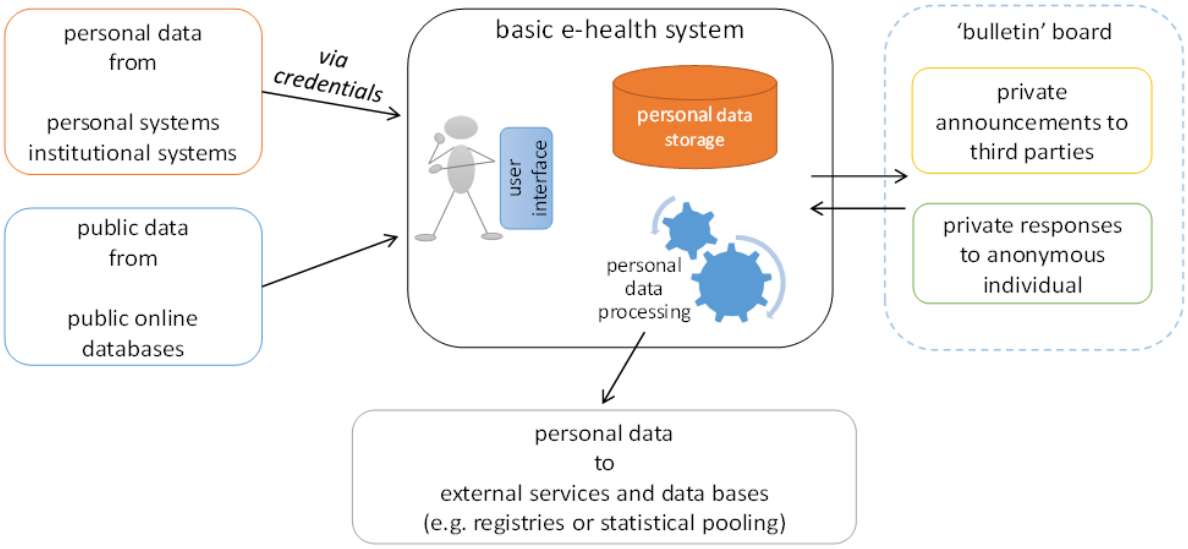

Figure 7. Modelling basic functionalities of a personal e-health system.

The CARRE advanced services of visual analytics and decision support are currently under way. A first visual interface for visualization and management of the personal data has been implemented. Figure 8 shows representative views of the visualization of personal data charts and the personalized risk factor projection.

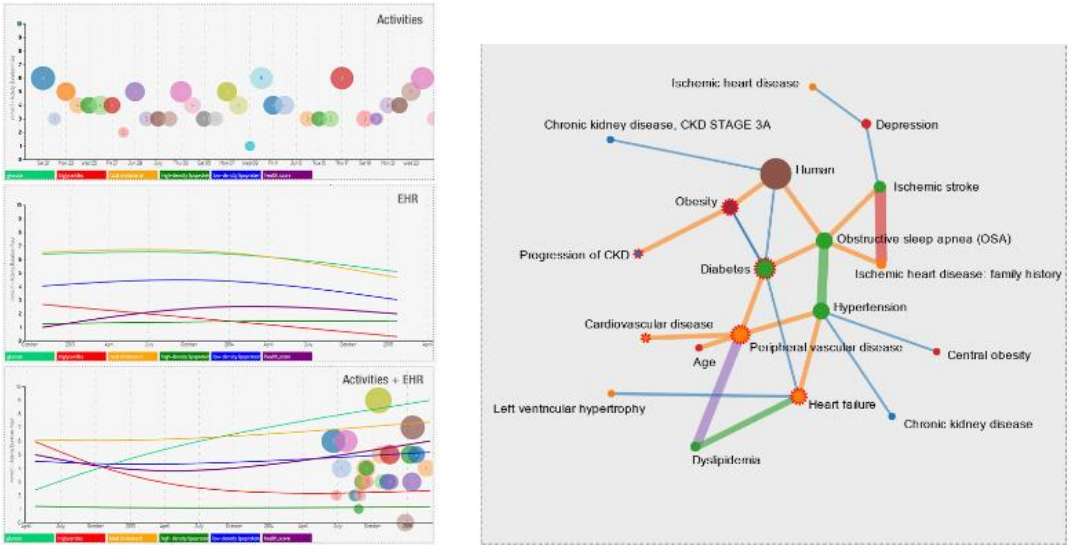

Figure 8. Example personal data charts (lelf) and a node-link diagram used to visualise risk factors (right).

We have conducted literature research and field analysis to drive the identification of CARRE use cases. Functional requirements were then derived and the system architecture has been designed with detailed identification of all functional units, data objects and system services. Based on these, we have initiated work on the evaluation methodology. To enable an informative approach to evaluation we have developed a generic model of patient empowerment as a cognitive process and mapped CARRE services to this model.

Finally, along with research and development work, we are following a thorough dissemination plan. So far, project results have been disseminated via 13 scientific publications, 4 invited presentations, 4 articles in newsletters, the CARRE *Let's CAR(R)E Together!* newsletter (29 articles), 3 press releases. In addition, the project has an active web presence via its web site, twitter, slideshare and other online social media.

Impact

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

The 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 website: http://www.carre-project.eu

CARRE Fact Sheet	
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
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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
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