A Demonstration of 4D Digital Avatar Infrastructure for Access of Complete Patient Information

Project acronym: MyHealthAvatar

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Interim Management Report 2

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ABSTRACT:
This deliverable reports the progress of the project within its first 30 months. The report is organised according to its progress within the 11 work packages.

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[1] **R**=Report, **P**=Prototype, **D**=Demonstrator, **O**=Other

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Contents

1 Executive Summary

Owing to the highly fragmented health systems in European countries, gaining access to a consistent record of individual citizens that involves cross-border activities is very difficult. MyHealthAvatar is an attempt at a proof of concept for the digital representation of patient health status. It is designed as a lifetime companion for individual citizens that will facilitate the collection of, and access to, long-term health-status information. This will be extremely valuable for clinical decisions and offer a promising approach to acquire population data to support clinical research, leading to strengthened multidisciplinary research excellence in supporting innovative medical care.

MyHealthAvatar will be built on the latest ICT technology with an aim of engaging public interest to achieve its targeted outcomes. In addition to data access, it is also an interface to access integrative models and analysis tools, utilizing resources already created by the VPH community. Overall, it will contribute to individualized disease prediction and prevention and support healthy lifestyles and independent living. It is expected to exert a major influence on the reshaping of future healthcare in the handling of increased life expectancy and the ageing population in Europe. This complies with the priority and strategy of FP7 ICT for healthcare, and constitutes a preparatory action aiming at the grand challenge on a “Digital Patient”, which is currently the subject of a roadmap in the VPH community.

This document reports the progress of the project within the second year. The report is organised according to its progress within the 11 work packages.

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1.1 Project background

The MyHealthAvatar project will focus on research and demonstration actions, through which the achievability of an innovative representation of the health status of citizens, named 4D MyHealthAvatar, will be explored. The 4D Avatar is anticipated as an interface that will allow data access, collection, sharing and analysis by utilizing modern ICT technology. It is expected to become the citizen's lifelong companion, providing long-term and consistent health status information of the individual citizen along a timeline representing the citizen's life, starting from birth. Data sharing will be encouraged, which will potentially provide to an extensive collection of population data to offer extremely valuable support to clinical research. The avatar will be equipped with a toolbox to facilitate clinical data analysis and knowledge discovery.

MyHealthAvatar can be described as a personal bag carried by individual citizens throughout their lifetime. It is a companion that will continually follow the citizen and will empower them to look after their own health records. This fits very well into the recent trend of developing patient-centred healthcare systems.

2 Work in Progress

This chapter describes the work progress according to the work packages.

2.1 WP1 Project Management

The objectives of this WP are:

- to ensure that the project attains its goals effectively: on time, to the specifications contained within the contract, and within the budget defined
- to ensure timely submission of all contractual deliverables
- to organise project meetings
- to elaborate and enforce quality procedures

A Project Management Office (PMO) has been established at BED who will monitor the project throughout its duration and be responsible for all non-research activities.

2.1.1 T1.1 Administrative and Financial Management: PM1=>PM36 (Task Leader: BED)

The PMO continuously monitors project activities in relation to the contractual work plan. The PMO will maintain the project Gantt chart, the risk analysis tool and other instruments that are necessary to ensure this level of monitoring, and update them, as required. The project status is constantly reviewed at meetings of the Steering Committee (SC). The SC will also be concerned with quality management.

The PMO has established a detailed administrative management framework, in conjunction with other partners; this includes templates for reports, deliverables, etc. Redmine has been selected as the management software to conduct consortium management.

Notably, pre-finance has been distributed to all the partners according to the proportion of their budgets.

All the partners have been in close contact with the project coordinator to contribute in all necessary project monitoring activities.

2.1.2 T1.2 Consortium Management: PM1 => PM36 (Task Leader: BED)

Descriptions of the procedures to be followed for reporting, dissemination have been provided and all partners have gained a common perspective and develop a common practice.

All these activities are coordinated by a project management software called Redmine, which is currently available at BED. Redmine is a flexible project management web application to allow multiple projects support, flexible role based access control, flexible issue tracking system, Gantt chart and calendar, news, documents & files management, feeds & email notifications, per project wiki, per project forums, time tracking.

By using Redmine, all the project tasks are recorded in Gantt Chart and are assigned to individuals. These tasks are subsequently tracked and watched by all the other partners. All the updates of the issues are closely monitored by the relevant partners by using automatic email notification and by using the project Gantt Chart. Other features such as document repository, news announcement,

wiki page are also used to ensure the consistent communication within the consortium and make sure everybody stays on the same page. By doing so, the individual tasks of the project fit well into the overall picture of the project.

So far the following meetings have been held:

- Kick off meeting, 27-28th March, 2013, Windsor, UK
- Technical Meeting, 1st – 2nd August, 2013, Crete, Greece
- 1st progress meeting, 12th September, 2013, Budapest, Hungary.
- 2nd progress meeting, 18-19th Feb, 2014, Luton, UK
- 3rd progress meeting, 18-19th Sept, 2014, Homburg, Germany
- Technical meeting, 22nd -23rd Jan, 2015, Luton, UK
- 4th progress meeting, 25th – 26th , 2015, Lincoln, UK
- Technical meeting, 1st – 2nd July, 2015, Crete, Greece

The next progress meeting (5th progress meeting) will be held in Athens, Greece, in 1st-2nd Oct, 2015.

A document repository has been built at Redmine, which contains all the templates for project deliverables, presentations etc.

2.1.3 WP1 conclusion

Also, the consortium is having bi-weekly Skype meetings to discuss recent technical and legal related issues.

Relevant deliverables

D1.1) Interim management report I: [month 6] – submitted

D1.2) Periodic report I: [month 12] – submitted.

D1.3) Interim management report II: [month 18] – submitted

D1.4) Periodic report II: [month 24] – submitted

D1.5) Interim management report III: [month 30] – submitted

D1.6) Periodic report III: [month 36]

Relevant milestones

MS011 Kick off meeting [month 1]- achieved.

2.2 WP2 User needs (1-9)

WP2 elaborates on the user needs and requirements for the proposed technological and clinical research infrastructure to develop the 4D Digital Avatar. The specific objectives include:

- Understand the state of the art
- Understand the user requirements
- Investigate the linkages to external sources

2.2.1 T2.1: State of the art review: PM1=>PM9 (Task Leader: USAAR)

2.2.2 T2.2: User needs and requirements: PM1=>PM6 (Task Leader: USAAR)

2.2.3 T2.3: User requirements and specifications for the linkage to external sources such as social networks and for the collaboration with other existing research projects: PM1=>PM9 (Task Leader: FORTH)

Relevant deliverables

D2.1) State of the art review related to the MyHealthAvatar environment: [month 9] – submitted.

D2.2) Scenario based user needs and requirements: [month 6] – submitted but an updated version is needed after the review meeting.

D2.3) Specification of the linkage to external sources and research projects: [month 9] – submitted.

Relevant milestones

MS021 Scenario based user needs and requirements [month 6]- achieved

2.2.4 WP2 conclusion

WP2 was completed in the first period so there is no specific activity to report. However, the activities of user requirement and use cases continue in WP7 and WP9.

2.3 WP3 Architecture and Integration (2-36)

The objective of this work package is to

- define the system's architecture and monitor its realization in the course of the project
- provide methodology for the integration with external sources such as hospital records, existing data and model warehouse, social network
- provide standards, guidelines and techniques in order to achieve the system integration
- investigate techniques to build a local cloud infrastructure to support data processing by utilizing resources within individual institutions.
- present a market review of open source APIs for MyHealthAvatar

2.3.1 T3.1 User requirement analysis :PM2=>PM4(Task Leader: FORTH)

This task was completed in the first period and there is no further activity to report.

2.3.2 T3.2 Architecture definition and design: PM2=>PM6(Task Leader: FORTH)

This task provides the architecture's blueprint and will continually monitor its implementation, with emphasis put, on the one hand, on the adherence to the standards and the technologies chosen, and on the objectives of the system.

We have been working to submit a new deliverable D3.8 for the MHA architecture which is complement to D3.2 submitted in year 1. D3.8 provides a more completed version for the MHA architecture.

However, D3.8 is an additional deliverable inserted at the request of the reviewers. It was made available to the reviewers at month 24 ahead of the review. We would appreciate the acknowledgement of this additional deliverable from the reviewers.

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2.3.3 T3.3 Architecture platform build, maintenance and security: PM2=>PM36(Task Leader: FORTH)

This task builds and maintains the structure of the architecture platform by investigating a number of key issues in infrastructure, resource management, data access and federation, computing resource. It deals with all the security aspects of the technological platform, ranging from user authentication, authorization, and auditing, to data integrity and privacy, to pseudo anonymization and re identification of patient data. It also focuses on interoperability by building as much as possible upon widely accepted security standards (e.g. OAuth, SAML, Liberty-Alliance, WS-*, XACML, etc). The current platform is shown in the following diagram – the task is on-going.

An early version of the platform was made available in June 2014 and it has been under testing by a number of participants.

2.3.4 T3.4 Methodologies to support link with external data sources: PM2=>PM33(Task Leader: FORTH)

This task considers the architecture to support the link of the 4D avatar with the external sources as an interface to extract data and information. These will include

1) Social network.
2) External data warehouse.
3) Hospital records. This looks into the feasibility of the links to the hospital systems to allow the exportation of the health related data of the patients from the linked hospital systems.

Currently the MHA platform is connected to Twitter.

One of the use cases (the Nephroblastoma case) will demonstrate the link of the MHA platform with an onco-simulation platform. The mechanism will allow us in the future to link to any other VPH based data warehouses. The onco-simulation platform has now been built and we are experimenting MHA APIs to allow them to be connected to MHA.

Meanwhile, we are also considering the link to OBTIMA and IndivoX (PHR) via the semantic layer.

For the hospital records, a hospital system has been built at FORTH with populations of synthetic patient data. We have successfully experimented the link with a Cassandra data repository. The next step is to link it to the MHA platform for the demonstration purpose.

Issue about linking to hospital system will be discussed in the section 2.3.8.

2.3.5 T3.5 Investigation of local cloud PM7=>PM18 (Task Leader: BED)

A MHA cloud has been formed including the nodes from Linode (a public cloud) and from a private cloud hosted by partner FORTH – more details are reported in the D3.5 and D3.8, respectively.

This task was completed in year 2.

2.3.6 T3.6 Market review of open source APIs for MyHealthAvatar PM19=>PM24 (Task Leader: BED)

The MHA APIs (v1 and v2) have been made available for internal testing among the consortium members that are developing use cases for demonstration purpose.

2.3.7 T3.7 Platform integration. PM13=>PM33 (Task Leader: FORTH)

The integration has started. The final architecture diagram has been agreed and this is reported in D3.8. Within the next 6 month the following components are to be integrated into the current version of the platform

1) a semantic search interface
2) a link to a hospital system (This will be a real hospital system running on the premises of partner FORTH with synthetic data only)
3) Viewing of clinical data on a timeline
4) Dicom image upload, which will allow the patients to update their Dicom images
5) Internal model repository (for educational purposes)
6) A semantic integration of individual profiles with integrated APIs.

2.3.8 WP3 Conclusion

In summary all related activities for WP3 were carried out as planned. All task activities are progressing as planned, in iterative cycles of refinement, and in close interaction and collaboration with all other WPs. The focus is on delivering mature and market relevant architectural specification for MHA system.

During the 2nd review there were issues raised by the reviewers w.r.t the link to hospital systems. The response for the clarification of this issue is as follows:

"This issue was repeatedly mentioned during the second review meeting and there was a clear doubt among the reviewers if the consortium has made a promise to link the MHA platform to a live running hospital for demonstration in the DoW. We have checked the DoW and we believe this is clearly not the case.

MHA is a demonstration and feasibility study action in which we need to describe the benefits of MHA in the long term under the assumption of positive outcomes from such a study. One of the envisaged scenarios was to link the MHA platform to hospital systems to allow the users to gain access to a long term health record and medical history. Given the complexity of legal and ethical issues such a demonstration can only happen via a "simulated" hospital system which is currently deployed at partner FORTH. The technical investigations have taken place and have been reported in D3.8. In addition, the legal partners will also investigate the legal requirements and restrictions on this issue and the outcomes will be reported in the upcoming deliverable D11.5. Notably, such investigations focused on the technical feasibility with an attempt of foreseeing future benefits in clinical and legal terms. We have checked through the DoW very carefully and we have found the following statement in the WP3 descriptions in the DoW:

" *Hospital records. This will look into the feasibility of the links to the hospital systems to allow the exportation of the health related data of the patients from the linked hospital systems. The predominant issue in this task relate to the security and the transformation of the data followed by the proper annotation in order to be compliant with the syntactic and semantic principles of the system. Notably, we do not expect to realize the physical link in the duration of this project due to complex legal issues. This will present as a feasibility study on the technical side, which will be in*

conjunction with the work on the legal side in WP11. A simulated database can be built to allow the investigation. "

Therefore, our targets in this particular issue were clearly and explicitly written in the DoW and we believe that the consortium has been consistent throughout the DoW and the actions taken in the work. We are very sorry if there is any confusion from the reviewers on this issues and we are more than happy to clarify this further if needed. "

Also, with respect to the public cloud, currently the data storage architecture is already based on a mixture of private-public cloud and the deployment is already completed. In other words, we have already investigated the feasibility and technical and legal terms on how MHA can be implemented in both private and public cloud environment. More details can be found in D3.8.

At the next stage the following activities will be carried out:

1) a semantic search interface
2) a link to a hospital system (This will be a real hospital system running on the premises of partner FORTH with synthetic data only)
3) Viewing of clinical data on a timeline
4) Dicom image upload, which will allow the patients to update their Dicom images
5) Internal model repository (for educational purposes)
6) A semantic integration of individual profiles with integrated APIs.

Relevant deliverables

D3.1) User requirements: [month 4] – submitted

D3.2) Architecture design: [month 6] – submitted

D3.3) Security measures and guidelines: [month 33]

D3.4) Technical report on the links with external data resources: [month 33]

D3.5) Report on local cloud infrastructure: [month 18] - submitted

D3.6) Report on the review of open source APIs for MHA: [month 24] - submitted

D3.7) Integrated platform with an evaluation report: [month 33]

Relevant milestones

MS031 First deployment of the architecture platform [month 9]: achieved

MS032 Simulated database to experiment links with hospitals [month 12]: achieved

MS033 Deployment of a local cloud [month 18]: achieved

MS034 Web interface for toolbox [month 24]: achieved

2.4 WP4 Semantic interoperability (2-33)

The objective of WP4 is to establish and formally specify the semantics-based conceptual substrate of the overall information system. More specifically the objectives of this work package are the following:

- Specification of a core Ontology describing multi-scale medical data, social activity and models.
- Specification of a mapping formalism to allow data extraction and integration.
- Specification of the algorithms & methodology for data and query translation.
- Ontology summarization and evolution
- Semantic Reasoning for Decision Supports

2.4.1 T4.1: Semantic Core Ontology PM2=>PM24(Task Leader FORTH)

This task has established Semantic Core Ontology. The detailed activity is reported in D4.2.

2.4.2 T4.2: Mapping formalism PM2=>PM24(Task Leader FORTH)

In this task, we intend to identify the requirements for mappings that bridge the Semantic Core Ontology with the information models representing the external information sources. The detailed activity is reported in D4.2.

This task was completed in year 2.

2.4.3 T4.3: Semantic Integration Methodology PM2=>PM24(Task Leader FORTH)

This task takes as input the mapping format and methodology established in task T4.2 and defines the necessary algorithms for data translation or query rewriting. The detailed activity is reported in D4.2.

This task was completed in year 2.

2.4.4 T4.4: Ontology Evolution and Semantic Summarization PM13=>PM33(Task Leader FORTH)

This task produces semantic summaries that constitute adequate representations and include anchors to complete ontological descriptions. The activities will be reported in D4.3

2.4.5 T4.5: Semantic Reasoning for Decision Support PM13=>PM33(Task Leader FORTH)

Semantic reasoning has started to support some use cases (CHF and osteoarthritis). In addition, external links such as IndivoX and OBTIMA will be linked to the MHA platform through the semantic layer – more work will be done in this direction in the rest of the project and will be reported in D4.4.

2.4.6 WP4 conclusion

The major achievement of this period:

1) the semantic core ontology for MHA has been generated
2) ontology mapping, integration and summarization have made progresses.
3) Semantic reasoning have been used in the implementation of some use cases (CHF and osteoarthritis)
4) Further links with IndivoX through the semantic layer is under way.

At the next stage the following activities will need to be carried out:

1) A semantic search engine that will allow patients to search for recommended educational material and documents for patients
2) A range of reasoning tools at the semantic layer, for example, an alert engine to issue health alert to patients
3) Link to IndivoX (PHR) at the semantic layer
4) Integration of personal profiles at the semantic layer with APIs

Relevant deliverables

D4.1) Requirements analysis for semantic core ontology: [month 4] – submitted

D4.2) Extension of the semantic core ontology: [month 24] - submitted

D4.3) Technical evaluation report of ontology including ontology evolution and summarization: [month 33]

D4.4) Semantic reasoning utilities for decision support: [month 33]

Relevant milestones

MS041 Initial proposal for the semantic core ontology [month 8] - achieved.

MS042 Definition of the mapping formalism [month 12] - achieved

MS043 Query rewriting and data translation [month 12]– achieved

MS044 Ontology evolution & summarization (Initial version & evaluation) [month 19]

MS045 Semantic reasoning utilities for decision support (initial version) [month 15]

2.5 WP5 Models and repositories (3-36)

This work package focuses on the development of clinical oriented repositories that will cover the needs of the MyHealthAvatar project. This involves the development of:

- a repository of models of special biomechanics and tumour growth and response to treatment including the dynamics of specific affected and/or critical organs.
- a data repository of multiscale data exploitable by the models. The aforementioned repositories will be tailored to the needs of the project. At the same time they will be generic enough to be usable by several different medical scenarios.

2.5.1 T5.1 Development of the models repository: PM3=>PM36 (Task Leader: ICCS)

The model repository is continuously being built. It will service to purposes:

- A general tool repository to patient self assessment of health, such as risk of having diabetes. It can also contain onco-simulation models for education purposes.
- A onco-simulation model repository used as an external service to be linked to the MHA platform – this use case will demo the value of the MHA platform in oncosimulations and the potential value of MHA in other VPH projects.

The build of the above two repositories are in good progress. The general tool repository will be integrated in 2-3 month time.

2.5.2 T5.2 A data repository for models: PM3=>PM36 (Task Leader: ICCS)

To response to the issues raised by the 1st year review, we have clarified the role of the data repository in WP5. It will be the data repository served to support the onco-simulation model repository which will be treated as an external service linked to the MHA platform.

We have also discussed the possibility of linking two FP7 projects together for data exchange: MHA and CHIC. Currently the discuss is still on-going. We have received a positive feedback from the CHIC project. However, many details will still need to be worked out and the feasibility will still need further exploration.

2.5.3 T5.3 Integration with the security framework: PM7=>PM36 (Task Leader: ICCS)

For the internal model repository can be integrated with the MHA framework stragithaway. It has also been agreed that we will need to create an admin role, who will be able to log in as an admin to manage the internal model repository.

For the external onco simulators, the integrated is related to the currently on-going discussions about linking to the CHIC data repository. The conclusions shall be presented in the next stage

2.5.4 WP5 conclusion

To reflect to the reviewers comments in year 2, activities are focused on:

1) clarify the roles of model/data repository in WP5 for the MHA platform
2) implementation of a general repository for patient self-assessment as well as for patient education
3) implementation of a onco-simulation platform that will be linked to the MHA platform as an external service to support the Nephroblastoma use case
4) The integration of the internal model repository will be completed very soon.
5) We have started the discussion of linking MHA and CHIC data repository in order to carry out more personalised onco-simulation.

Relevant deliverables

D5.1) Model and clinical data repositories design: [month 12] – submitted.

D5.2) Model and clinical data repositories interfaces & evaluation report: [month 36]

Relevant milestones

MS051 Model and clinical data repository schema [month 12] – achieved.

MS052 Web services for the model and the clinical data repositories [month 24]

MS053 Security of the model and the clinical data repositories [month 30]

MS054 Final integration of the model and the clinical data repositories [month 32]

2.6 WP6 Data and repositories (2-36)

The main objectives in WP6 are:

- to develop data collection utilities for support data contribution from users with minimal input

- to build a data repository to store health related data of individual citizens collected from the web and mobile apps.
- to experiment the Linked Data approach to facilitate the flourish and reuse of data, including data search and reasoning.

2.6.1 T6.1 Data collection utilities PM2=>PM12 (Task Leader: BED)

The platform can currently be connected to Withings O2 plus, Fitbit, Moves. We will continue to work on other sensors that allow for the measuring of blood pressure, weight, and other health related information. Notably, a MHA mobile app is currently developed for easy data collection purpose, which will cover voice input, mood input and possible food input as well.

This task is completed in year 2

2.6.2 T6.2 Data collection from online patient diary PM13=>PM33 (Task Leader: BED)

The interface was made available in June 2014 is currently under testing. However, we found that not many participants are using the online diary to enter their activities. Therefore in the updated version we will look into a new layout to make the data entering more explicit.

We have completed a number of major iterations of the MHA app. One of the major features of the MHA app is a chat-based journal to allow easy patient diary using a chatting interface. A range of data can be collected, including mood, food, healthcare questionnaires. The users can record their diary via a multimedia approach, such as text, voice, photos. The details will be reported in the upcoming deliverables.

2.6.3 T6.3 Data repository for health information PM7=>PM36 (Task Leader: BED)

The Cassandra data repository is continuously being used as the core data repository to collect health related information for patients/citizens. It has a flexible scheme that allows for easy expansion for new data structures. Along side we have also made the MHA APIs available to the access of the data by external applications.

The data repository is at the heart of the MHA platform and it supports all the components of the platform. Currently, we have done a few rounds of iteration for the MHA APIs, to make them robust, and to allow them to incrementally support a wide range of input data from multiple sources, and to progressively remove bugs that were discovered during the development process, and to support the development of the high-end use cases. Overall we found this is a very time and resource consuming work.

2.6.4 T6.4 RDF data repository PM7=>PM36 (Task Leader: BED)

The work is currently under close collaborations with WP4. In WP6 the work has focused on lifestyle and movement data. The work will be reported in the upcoming deliverables.

2.6.5 T6.5 Data reasoning PM7=>PM33 (Task Leader: BED)

We are currently under the development of developing lifestyle reasoning. A new initiative have been proposed for a new suite called LifeTracker, which will allow:

- Data mining for life patterns (24 hours) of individual citizens (through data aggregation).
- Data mining for important event ranking

- Data mining for the travel patterns of individuals
- Data mining for activity extractions
- Data mining for exploring data co-relationships.

The details and outcomes will be reported in the upcoming deliverables.

2.6.6 T6.6 Integration with the security framework (PM7-PM36) (Task Leader: BED)

We have investigated API Security with OAuth 2.0 using different approaches for access grant, such as resource owner password grant; used by demo platform user authentication; implicit grant (Used by demo platform JavaScript request); Authorization Code Grant (Under implementation & testing used by 3rd server-side request0.

This task is still on-goiing.

2.6.7 T6.7 Collection of multiscale datasets PM3=>PM24(Task Leader: FORTH)

The dataset is available but the use by the whole consortium members are subject to another ethical approval which is currently undergoing at FORTH and its associated clinical partner. Details are reported in D6.6.

This task was completed in year 2.

2.6.8 WP6 conclusion

The major achievements in this period are:

- New data collection utilities such as Fitbit, Moves, Withings have been integrated into the system.
- A MHA mobile app is being developed & the iteration has gone through a few releases
- The online patient diary available with the MHA app, which has been published in a few testing versions.
- The data repository is developed and a number of releases have been published in order to support an increasing range of data types and new demands from high end use cases.
- We are currently working on data mining under a number of new initiatives and it is under close collaboration with WP4
- The security framework is developed and under testing

Relevant deliverables

D6.1) A set of data collection utilities & evaluation report: - submitted [month 12]

D6.2) Design for data and RDF repositories: submitted [month 12]

D6.3) Data & RDF repository & evaluation report: [month 36]

D6.4) Data reasoning utilities for decision support & evaluation report: [month 33]

D6.5) Initial report on data collection methods and plans: [month 9] – submitted.

D6.6) Final comprehensive datasets: [month 18] – submitted

Relevant milestones

MS061 Initial collection of data [month 9] – achieved

MS062 data & RDF repository schema [month 12]– achieved

MS063 Data reasoning utilities for decision support(initial version) [month 15]

MS064 Web services for data & RDF repositories [month 24]

MS065 Security of the data repository [month 30]

MS066 Final integration of the data repository [month 32]

2.7 WP7 Use cases (Scenarios) (10-18)

The objective of this WP is to build scenarios and use cases based on the user needs identified in WP2

2.7.1 T7.1: Scenarios and use cases for MyHealthAvatar: PM10=>PM18 (Task Leader: USAAR)

We have been working on the selection of the clinical use cases out of those proposed in Year 1. This was recommended by the 1st year report. Eventually 4 cases were selected and their detailed descriptions were given in D7.1.

Relevant deliverables

D7.1) Description of scenarios and use cases for MyHealthAvatar: [month 18] – submitted.

2.7.2 WP7 Conclusion

The major achievements are:

- Final set of clinical use cases have been selected
- D7.1 has been submitted with a detailed description of the selected use cases.

This WP is closed in year 2 and new activities are carried out under WP9.

2.8 WP8 Avatar centred visual analytics (3-33)

The objectives of this WP are

- To provide a set of visualization tools for model and data analysis
- To provide a set of display functionality for avatar rendering

2.8.1 Task 8.1 Avatar modelling and rendering suite PM3=>PM18 (Task Leader: BED)

An initial version of the avatar rendering suite has been made available and are under testing. In the future version this will be linked to the patients' data as a data browser tool.

This task was completed in year 2. However, in light of reviewers comments during the second year review, we are also exploring a 2D avatar approach as an alternative to 3D.

2.8.2 Task 8.2 Key techniques of visual analysis PM4=>PM33 (Task Leader: BED)

The following data visualization views are made available to display users' data

- Dashboard
- Calendar view

- Map view
- Timeline view

The interface has been significantly updated, which shows a number of advanced features to explore interactive life pattern & lifestyle exploration.

The visual analytics has also been integrated into the profile page, which will visualise health information from PHR in a reporting style with a 2D avatar integrated in. We also plan to enable interactive visualization on the avatar.

Also, under the new initiative of LifeTracker, we are preparing another major upgrade of the visual interface of the MHA system.

2.8.3 Task 8.3 A visual data analysis suite PM19=>PM33 (Task Leader: BED)

The suite will allow for the following functionalities:

- Life pattern summary
- Highlighting of key events
- A multi-layer timeline allowing for the selection of a time period at different scales
- Coordinated views between map, timeline, calendar and event list and life patterns

The LIN team has developed techniques to allow for the evaluation of health status
More details will be reported in the upcoming deliverables.

2.8.4 Task 8.4: Multi-scale medical image analysis PM6=>PM27 (Task Leader: LIN)

It has been decided that low resolution images will be displayed on the timeline to support patinets' views. This is under ipmlementation in the project.

2.8.5 WP8 conclusion

The major achievements will include:

- The 3D/2D avatar suite
- Life pattern summary
- Highlighting of key events
- A multi-layer timeline allowing for the selection of a time period at different scales
- Coordinated views between map, timeline, calendar and event list and life patterns

Notable, with respect to Task 8.3 and Task 8.4, the following issues were reported in the second year report:

"Given the new definition of the core service of MyHealthAvatar, Task 8.4 should be renamed as medical image visualization for patients.

Significant new efforts have been in intelligent data analysis and data validation to extract useful knowledge from the data for patients – this was not written in DoW and we suggest to report! This in D8.3. "

Relevant deliverables

D8.1) Display suite for avatars & evaluation report: [month 18] – submitted

D8.2) Avatar-centred visual analytics suite & evaluation report: [month 33]

D8.3) A multi-scale medical image analysis toolbox: [month 27]

Relevant milestones

MS081 Avatar rendering (initial version) [month 12] – achieved

MS082 Key techniques for visual analytics (initial version) [month 18] - achieved

MS083 Visual data analysis suite (initial version) [month 24] – achieved.

MS084 Key techniques for multi-scale analysis [month 15] - achieved

2.9 WP9 Demonstration and evaluation (19-36)

This WP will guide the project in a way that the scenarios and use cases specified in WP7 can be demonstrated at the end of the project. This includes the following objectives:

- to describe and to the developmental process
- to test and evaluate demonstrators at each level of the development
- to demonstrate MyHealthAvatar at the end of the project at a conference

The work has been carried out closely with WP7 and a full description and plan of the implementation of all the 4 clinical use cases have been described in D91.

The tasks include:

- The development of the demonstration via 4 high-end use cases
- Discuss of the ideas for linking data repository of MHA with CHIC
- Define evaluation questionnaires
- Implementation of online questionnaires
- Preparation of evaluation workshops
- Preparation of demo account for the evaluation
- Preparation of demo videos
- Outreach to get in touch with external participants for evaluation

Conclusion

During the second review there were issues raised about the involvement of real patients. Here are the response:

"While the first year review has casted a great focus on patient/citizen empower as the benefit of the MHA platform, clinical data integration has been the focus in the second year review as we have faced many questions regarding clinical data integration. In particular, the reviewers have asked for the involvement of "real patients" and particularly "elderly patients". Please note that there was no explicit requirement on this in the first review report, despite the fact that we have stated the difficulties of having real patients in a range of use cases of the project and our intention of using healthy participants and synthetic patients were made clear through the first review and through the deliverables in D9.1

Recruiting "real patient" in project involves ethical issues with a highly complex nature and it will need to go through ethical procedures in hospitals, which will take a very long time. We believe that it will be extremely hard to achieve this during the remaining time of the project. However, we will make a great effort for this target by:

1) trying our best to recruit patients through our clinical contact inside/outside the project. At USAAR real patients will be involved in testing the usability of the system (without contributing their real data which will need complicated ethical process).
2) involving real patients to use the platform from other related projects, such a MyLifeHub.
3) continuing our effort to promote the platform among healthy participant"

Relevant deliverables

D9.1) Definition of the demos: [month 21]

D9.2) Development of demonstrators: [month 36]

D9.3) Report on the clinical acceptability and evaluation of MyHealthAvatar and future ecommendation: [month 36]

D9.4) Demonstration of MyHealthAvatar: [month 36]

Relevant milestones

MS091 Demo of MyHealthAvatar (initial version) [month 30]

2.10 WP10 Dissemination and exploitation (1-36)

The objectives of this WP include:

- to inform all internal and external stakeholders about the project results and the implications that these results might have for the research, clinical and industrial users;
- to communicate the availability of the technology to potential users and to import the technology into suitable application domains.

2.10.1 T10.1 MyHealthAvatar Web-site and dissemination materials: PM1=>PM36 (Task Leader: ICCS)

Website has been developed and is currently maintained by ICCS – see http://www.myhealthavatar.eu/. Flyers have been made

2.10.2 T10.2 Publications: PM1=>PM36 (Task Leader: ICCS)

A number of new publications have been made.

2.10.3 T10.3 workshop: PM25=>PM36 (Task Leader: BED)

We have started the planning of the workshop. For a more effective dissemination purpose, we have decided to organised a number of workshops alongside some major conferences where we can have access to targeted user groups. Three of them are currently on the way:

1) ICT 2015, Oct 2015, in Lisbon
2) MobileHealth, Oct 2015, In London

3) IEEE IoTBDH, Oct 2015, Liverpool

These events will be run alongside evaluations and we will ask the participants to provide us with feedbacks on the system.

Also, we will run a number of small workshops within the partnership organisations of the project. These workshops will target students and staff members who are not working on the projects and who have a wide range of background in computer science, healthcare and sport science, etc. The purpose is two-fold:

1) Dissemination for MHA outcome
2) Evaluation

At BED currently the following workshops are under plan

1) A workshop in Nov by students with computer science background
2) A workshop in Dec by students with sport science background
3) A workshop in Dec by students with public health background

2.10.4 T10.4 Exploitation: PM19=>PM36 (Task Leader: ASTRID)

The exploitation work has started and plans for future exploitation is given in D10.4. A business plan will be given in D10.5

2.10.5 WP10 conclusion

The main achievements include:

- New publications by the partners
- Preparation of the business plan D10.5.
- Workshops of MHA are under plan

Relevant deliverables

D10.1) External project website: [month 3] – submitted.

D10.2) Dissemination plan: [month 12] – submitted.

D10.3) Workshop for dissemination: [month 33]

D10.4) Exploitation plan: [month 24] - submitted

D10.5) Business plan: [month 36]

2.11 WP11 Ethical and IPR

The objectives of this WP include:

- Reviewing and analyzing the European and relevant national legislation on data protection, data security and ownership of (personal) data in reference to the data generated and processed within the project;

- Doing a survey on strengths and weaknesses of the European data protection framework in supporting the patient to keep control about their personal medical information in the MyHealthAvatar-scenario;
- Illustrating the impact of intellectual property on ownership of data processed in a 4D-Avatar and its software
- Creating legal and ethical guidelines concerning the use of the final platform; and
- Serving as a legal/ethical helpdesk for the project

2.11.1 Task 11.1 The legal and ethical framework PM1=>PM24 (Task Leader: LUH)

Task completed. D11.1 is submitted which describes this task in details.

2.11.2 Task 11.2. Survey on strengths and weaknesses of the European data protection framework in supporting the patient in scenarios like MyHealthAvatar PM13=>PM24 (Task Leader: LUH)

Task completed. D11.2 is submitted which describes this task in details.

2.11.3 Task 11. 3. Understanding the Legal and IPR regime in MyHealthAvatars PM25=>PM30 (Task Leader: LUH)

The task will show that data protection is not the only legal framework of relevance but that issues of intellectual property (on data, software, algorithms and concepts) is of equal importance. Some initial work has been carried out to understand the requirements of legal and IPR issues in the project. An internal document has been circulated within the consortium.

2.11.4 Task 11.4 Defining the rules for the exploitation of the platform after the project's end PM25=>PM36 (Task Leader: LUH)

This task will cover the data protection and intellectual property rules that need to be obeyed in the exploitation phase of the project in order to guarantee compliance with the relevant legal regime. This task has not started yet.

2.11.5 Task 11.5 Legal and ethical helpdesk PM1=>PM36 (Task Leader: LUH)

The activities include:

- Provide legal and ethical advice to the consortium
- Create consent forms for participants to use the platform.

2.11.6 WP11 conclusion

The major achievements include:

- Submission of D11.1 and D11.2
- Legal and ethical helpdesk for the project.
- Preparation of e-consent in the support of outreaching to the public users
- Preparation of an open-source based approach for exploitation
- Preparation of the third party licence
- Preparation of the CHIC-MHA agreement for linking the data repositories

Relevant deliverables

D11.1) The ethical and legal framework of MyHealthAvatar: [month 24] - submitted

D11.2) Survey on strengths and weaknesses of related European data protection framework: [month 24] - submitted

D11.3) Legal and IPR-related issues in patient centred solutions like MyHealthAvatar: [month 30] – submitted

D11.4) Legal framework for the exploitation of MyHealthAvatar: [month 36]

3 Appendix A

Response to the MyHealthAvatar 2nd review report July 2015

There have been 1 technical meeting organized by FORTH and TEI-C in Heraklion and a number of Skype meetings between the consortium members to discuss the outcome of the review. We really appreciate all the constructive comments from the reviewers. Meanwhile, we would like to make clarifications about some issues:

- "Link to hospitals"

This issue was repeatedly mentioned during the second review meeting and there was a clear doubt among the reviewers if the consortium has made a promise to link the MHA platform to a live running hospital for demonstration in the DoW. We have checked the DoW and we believe this is clearly not the case.

MHA is a demonstration and feasibility study action in which we need to describe the benefits of MHA in the long term under the assumption of positive outcomes from such a study. One of the envisaged scenarios was to link the MHA platform to hospital systems to allow the users to gain access to a long term health record and medical history. Given the complexity of legal and ethical issues such a demonstration can only happen via a "simulated" hospital system which is currently deployed at partner FORTH. The technical investigations have taken place and have been reported in D3.8. In addition, the legal partners will also investigate the legal requirements and restrictions on this issue and the outcomes will be reported in the upcoming deliverable D11.5. Notably, such investigations focused on the technical feasibility with an attempt of foreseeing future benefits in clinical and legal terms. We have checked through the DoW very carefully and we have found the following statement in the WP3 descriptions in the DoW:

" *Hospital records. This will look into the feasibility of the links to the hospital systems to allow the exportation of the health related data of the patients from the linked hospital systems. The predominant issue in this task relate to the security and the transformation of the data followed by the proper annotation in order to be compliant with the syntactic and semantic principles of the system. Notably, we do not expect to realize the physical link in the duration of this project due to complex legal issues. This will present as a feasibility study on the technical side, which will be in conjunction with the work on the legal side in WP11. A simulated database can be built to allow the investigation.* "

Therefore, our targets in this particular issue were clearly and explicitly written in the DoW and we believe that the consortium has been consistent throughout the DoW and the actions taken in the work. We are very sorry if there is any confusion from the reviewers on this issues and we are more than happy to clarify this further if needed.

- "Involvement of real patients"

While the first year review has casted a great focus on patient/citizen empower as the benefit of the MHA platform, clinical data integration has been the focus in the second year review as we have faced many questions regarding clinical data integration. In particular, the reviewers have asked for the involvement of "real patients" and particularly "elderly patients". Please note that there was no explicit requirement on this in the first review report, despite the fact that we have stated the difficulties of having real patients in a range of use cases of the project and our intention of using healthy participants and synthetic patients were made clear through the first review and through the deliverables in D9.1

Recruiting "real patient" in project involves ethical issues with a highly complex nature and it will need to go through ethical procedures in hospitals, which will take a very long time. We believe that it will be extremely hard to achieve this during the remaining time of the project. However, we will make a great effort for this target by:

4) trying our best to recruit patients through our clinical contact inside/outside the project. At USAAR real patients will be involved in testing the usability of the system (without contributing their real data which will need complicated ethical process).
5) involving real patients to use the platform from other related projects, such a MyLifeHub.
6) continuing our effort to promote the platform among healthy participants

[1]

- Deliverable D3.8

D3.8 is an additional deliverable inserted at the request of the reviewers. It was made available to the reviewers at month 24 ahead of the review. We would appreciate the acknowledgement of this additional deliverable from the reviewers.

In the reminder we will provide a summary of the actions that we plan to take in order to address the issues raised in Annex 2 point 1B and 1C.

B. Recommendations concerning the period under review

1. *The Consortium provided a well elaborated document with responses to the reviewers' comments in response to the 1st year's review. An overarching recommendation is that the Project lacks a clear definition of the value it adds to each existing and prospective use case. In order for the MHA approach to succeed, potential stakeholders – particularly application developers and curators of datasets – need to be aware of what MHA can offer. A brief, clear description of what MHA is and what it isn't should be included in further dissemination/exploitation activities by the Consortium.*

Answer: We will explore this through activities led by the business partner LarkBio and will report the activities in D10.4

[2]

2. *In addition, if the Project is expected to cater to software developers and data curators, then this needs to be clearly stated in the relevant reports and a set of tools expected by such stakeholders (particularly APIs and the relevant documentation) should be provided. The*

Consortium has already gone to some lengths to address this concern but more effort is required if a PaaS-like solution is envisioned by the Consortium.

Answer: The processes that regulate the use of APIs by third party developers will be developed by the legal partner LUH and shall be reported in D11.5. The technical partners will use these guidelines to implement user interfaces and services that will allow a third party to register and to be granted access to the APIs.

We do not envisage MHA to provide a PaaS-Like solution . Our general perception is that the MyHealthAvatar platform is in essence a data and information provider of individual citizens for clinical and health related applications and services.

C. Recommendations concerning future work

1. *Linkage between individual health data and MHA is a key component of the DoW and needs to be reported at the next review with a separate deliverable in WP9. This will enable a more complete demonstration of the platform and user feedback from patients and clinicians, complementing healthy participants in other implementations of the use cases.*

Answer: As mentioned earlier in this document, the actions that will be taken include:

- Technical feasibility study by linking the platform to the hospital system (a real system but not daily running)
- Implementing the functionality to allow the patients to upload clinical records (e.g. patient summary) and images (dicom images) to the platform.
- trying our best to recruit patients through our clinical contact inside/outside the project. At USAAR real patients and clinicians will be involved in testing the usability of the system (without contributing their real data which will need complicated ethical process).
- involving real patients and clinicians to use the platform from other related projects, such a MyLifeHub.

2. *If migration of MHA software and data to public cloud resources is foreseen then a clear roadmap should be prepared and followed as this is not a straightforward task.*

Answer: Currently the data storage architecture is already based on a mixture of private-public cloud and the deployment is already completed. In other words, we have already investigated the feasibility and technical and legal terms on how MHA can be implemented in both private and public cloud environment. More details can be found in D3.8.

3. *More attention should be devoted to integration of social media in the patient activity monitoring process, as proposed in the DoW. The issue has been only briefly addressed in Year 2 deliverables and it is not clear to what extent such data can be acquired and put to use in the context of the presented use cases.*

Answer: The current version of the platform can integrate Twitter by publishing data in Twitter (for dissemination and promotion purpose) and by collecting twits. The technical implementation of the above two functionalities have been completed.

With respect to the information extraction from the collected twits, we plan to carry out experiments to explore at what level we can extract meaningful information from the twits. However, extracting health information from unstructured twits is a huge challenge. Within limited resources of MHA we believe we shall focus on the infrastructure that enables the twits collection, allowing for the potential of future works in this direction. Due to the resource restriction we do not foresee the possibility of significant work in data processing in twits.

4. *The acceptance of MHA by targeted end users is a key component of the project. Thus, real end users have to be involved. In a separate deliverable of WP9, results of such an evaluation process have to be reported. While it is acknowledged that recruiting participants is an effort, online surveys constitute an appropriate means to collect large volumes of data with limited effort. However, those should be complemented by data from personalised end-user samples (i.e. not only online). Focus groups also are an appropriate means of collecting data on acceptance of MHA and the mandatory prerequisites for its usage. For each use case, feedback should be obtained from targeted end users.*

Answers: The project will devote every effort in order to achieve as much direct participation from the end-users (i.e. patients, citizens and doctors) as possible. To achieve this, a number of activities are already taking place: USAAR will contact the participants who were involved in the first round of the MyHealthAvatar survey, and we are continuing to communicate with the external projects who will probably use the MyHealthAvatar platform, such as MyLifeHub (an UK EPSRC project). For cases with no possibility of involving end-users directly in the duration of the project, we will consider to use synthetic data for the demonstration.

5. *The management report and the presentations during the meeting should be more explicit about the achievements of the period in question. In particular, the following issues should be clearly addressed: what has been done, and what remains to be done, with an explicit map of the achievements in the review period set against the milestones in the DoW; the extent to which the principles listed on page 3 of the DoW have been met and the technical benefits on page 4 achieved, a clear statement of any deviations from the DoW.*

Answers: Yes, we will do it.

6. *The Consortium was unable to manage the allotted time during the review. The Consortium is strongly advised to practice presentations prior to the meeting and take measures if the assigned time slot is overrun by the presenter, during the preparation and also during the review meeting.*

Answers: Yes, we will do it.

7. *Publications should be listed in the management report and copies made available for review in a secure environment e.g. in Redmine. Other means of dissemination should also be outlined in the management report.*

Answers: Yes, we will do it.

8. *Links with other VPH projects e.g. Tumor, ContraCancrum, ACGT and P-Medicine as well as H2020 programmes e.g. iManageCancer need to be explicitly reported in the deliverables.*

Answers: Yes, we will do it.