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

Project acronym: MyHealthAvatar

Deliverable No. 2.3
User requirements and specifications for the linkage to external sources such as social networks and for the collaboration with other existing research projects

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PP	Restricted to other programme participants (including the Commission Services)	
RE	Restricted to a group specified by the consortium (including the Commission Services)	
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ABSTRACT:
This deliverable is presenting the user requirements and specifications for the linkage to external sources such as social networks and for the collaboration with other existing research projects. The first part presents the EU funded projects with possibility to incorporate their progress and achievements. The next parts describe the social networks and more specifically the online social networking platforms with their developer related resources and the top personal health social networking services.

KEYWORD LIST:
User needs, requirements, specifications, social networks, collaboration with research projects.

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

[2] **PU**=Public, **PP**=Restricted to other programme participants (including the Commission Services), **RE**=Restricted to a group specified by the consortium (including the Commission Services), **CO**=Confidential, only for members of the consortium (including the Commission Services)

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Contents

1 Executive Summary

This document focuses on the user requirements and specifications for the linkage to external sources such as social networks and for the collaboration with other existing research projects. In the first part we present relevant EU funded projects whose progress and achievements could be incorporated in MyHealthAvavatar..

The next parts of this document describe the social networks and especially the online social networking platforms with their related resources for developers and the top personal health social networking services.

All presented resources are analysed in the terms of the identified end user needs and requirements. As result, the table template below, named 'End User Needs and Requirements Table', is populated with the relevant text and results.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
End User Description	End Users' needs	End Users' requirements	Development priority

The conclusion chapter is presenting the concluding table with all identified end user needs and requirements for the linkage to external sources such as social networks and for the collaboration with other research projects. All presented results are proposed to be discussed and decided in the frames of WP 7, Task 7.1.

2 Virtual Physiological Human (VPH)

The Virtual Physiological Human (VPH) is synonymous with a programme in computational biomedicine that aims to develop a framework of methods and technologies to investigate the human body as a whole. It is predicated on the transformational character of information technology, brought to bear on that most crucial of human concerns, our own health and well-being.

Additionally, VPH is a major European e-Science initiative intended to support the development of patient-specific computer models and their application in personalized and predictive healthcare. The VPH Network of Excellence (VPH-NoE)[3] project is facilitating interaction between the various VPH projects and addressing issues of common concern. A key deliverable is the 'VPH ToolKit' - a collection of tools, methodologies and services to support and enable VPH research, integrating and extending existing work across Europe towards greater interoperability and sustainability.

Researchers from the VPH-NoE project concluded that a single monolithic 'toolkit' is incapable of addressing the needs of the VPH. Rather, the VPH ToolKit should be considered more as a 'toolbox' of relevant technologies, interacting around a common set of standards. The latter apply as well to the information used by tools, including any data and the VPH models themselves, and also to the naming and categorising of entities and concepts involved.

2.1 VPH Toolkit

Currently the VPH ToolKit[4] encompasses many elements, reflecting the multi-faceted arena of VPH research, and some of the main developments and reported activities are related to:

- **Standards:** models, data, ontologies, and infrastructure interoperability. VPH-NoE's standards working group (VPH-SWG) has been established, which is primarily coordinated by VPH-NoE stakeholders, and works in consultation with the broader VPH research community (academic, industrial, and clinical).
- **Imaging tools:** One of the main objectives of VPH-NoE's imaging subgroup is to develop an online help tool called GUIDE (Guidelines for Image Development Environment) which will be part of the VPH ToolKit portal. The purpose of this tool is to guide users - developers, researchers, and clinicians - in choosing the proper biomedical image analysis tools for their work (software, libraries, etc.), and to provide support enabling their sharing and open use.
- **High performance computing:** Computational infrastructure within the EU includes EGEE providing low-end clusters, and DEISA providing supercomputer class resources. The VPH-NoE has obtained access to both of these infrastructures for the VPH researchers; to EGEE through the EGEE Biomedical Virtual Organisation, and to DEISA through a 'Virtual Community' allocation.
- **VHP ToolKit portal website.** The ToolKit portal website is anticipated to be a key resource for the community.

[3] The Virtual Physiological Human Network of Excellence (VPH NoE), 2008-2013, http://www.vph-noe.eu [November 2013]

[4] VPH NoE ToolKit, http://toolkit.vph-noe.eu [November 2013]

MHA project will benefit by being focused on identifying the synergies and the frames for (re)using, implementing, exploiting, and integrating VPH-NoE's achievements and realisations. This approach is suggested as one of the major project requirements.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, healthcare professionals	Integrate the results and achievements of the VPH Network of Excellence (VPH-NoE) project	Access, integration and usage of the VPH ToolKit elements	To be discussed and decided in the frames of WP 7, Task 7.1.

3 eHealth Research Projects

3.1 p-medicine

p-medicine[5] (From data sharing and integration via VPH models to personalized medicine) is a 4-year Integrated Project co-funded under the European Community's 7th Framework Programme aiming at developing new tools, IT infrastructure and VPH models to accelerate personalized medicine for the benefit of the patient.

In p-medicine 19 partners from 9 European countries and Japan have dedicated themselves to create support and sustain new knowledge and innovative technologies to overcome current problems in clinical research and pave the way for a more individualized therapy.

In connection with the scientific/technical dimensions of the work p-medicine will develop a data warehouse and a workbench with a tools repository. Heterogeneous pseudonymized/anonymized data from different origins will be stored in a data warehouse for further use by the scientific community. Clinical data will be exploited coming from hospital information systems and clinical trials. The legal framework of the project, which is based on the results of ACGT (Advancing Clinico-genomic trials), will be further developed and will guarantee data privacy and security. Most important for p-medicine are validated tools and services that provide interfaces to allow interoperability with biobanks, genetic databases, and medical imaging systems and data warehouses. These tools have to meet requirements to be used in large, international multicentre clinical GCP conform trials and need to be able to be integrated into existing systems used by ECRIN (European Clinical Research Infrastructures Network) and other communities. This includes aspects like data security by adopting the legal and ethical framework based on international requirements and approved concepts for anonymization and pseudonymization including validation. Previous R&D work done in European funded projects like ACGT, ContraCancrum and ECRIN.

All scheduled activities are structured in a way to produce a coherent and integrated work plan. p-medicine consists of different innovative and interrelated components that will be integrated to form the p-medicine environment. The R&D work will be continuously influenced by the interaction between the research and verification components of the project. P-medicine will actively seek to re-adjust its research activities and objectives based on evidence as a result of a quality assurance process within the work plan. It is the final goal of this project to develop the p-medicine environment to a self-sustaining legal body that will further develop the vision of this project fostering personalized medicine.

p-medicine will collaboratively develop advanced re-usable clinical trial driven multi-scale cancer models. As p-medicine will explicitly integrate an impressively larger number of biocomplexity levels, spanning from the quantum chemical level up to the physiological system level, will study different cancer types and will also address pathogenesis it might be viewed as the precursor of the "second generation" of Oncosimulators. On top of that, the direct and orchestrated involvement of Cancer Hospitals throughout Europe will provide a large number of cases per year for the optimization and validation of the p-medicine Oncosimulator, which is expected to bring in silico oncology a big step further. Such an anticipated outcome would be another European first. As p-medicine is driven by clinicians, validated by clinical relevant use cases and focusing its research and development on several pressing needs in healthcare their successful resolution will have significant and far-reaching implications.

[5] p-medicine, http://p-medicine.eu [November 2013]

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, healthcare professionals, general public	ObTiMA integration	Implementation of the Use Case/Scenario: Bidirectional linkage to ObTiMA	To be discussed and decided in the frames of WP 7, Task 7.1.
All end-users	Data protection and data security framework	Usage and integration of the p-medicine project deliverable D5.1 Setting up of the data protection and data security framework	
Researchers, healthcare professionals	3D visualised cancer models	Integration of the p-medicine's re-usable clinical trial driven multi-scale cancer models	

3.2 CHIC

The CHIC project[6] proposes the development of clinical trial driven tools, services and infrastructures that will support the creation of multiscale cancer hypermodels (integrative models). CHIC aspires to make a breakthrough in multiscale cancer modeling through greatly facilitating multi-modeller cancer hypermodelling and its clinical adaptation and validation. Standardization of model description and model "fusion" will be two of the core means to achieve this goal. The creation of such elaborate and refined hypermodels is expected to sharply accelerate the clinical translation of multiscale cancer models and oncosimulators following their prospective clinical validation (in silico oncology).

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, healthcare professionals	3D visualised cancer models	Integration of the CHIC clinical trial driven multi-scale cancer models	To be discussed and decided in the frames of WP 7, Task 7.1.

[6] CHIC project, http://chic-vph.eu [November 2013]

3.3 DISCIPULUS

DISCIPULUS project[7] is an undertaking established by the European Commission in October 2011 to set up a roadmap for the "digital patient". The Digital Patient term is an envisaged super-sophisticated computer program that will be capable of generating a virtual living version of your(our)self. When this is achieved, it will be possible to run 'simulations' of health and disease processes on the virtual or 'digital' you, and use the results to make predictions about your real health. It will also be possible to determine the best treatment specifically for you. This is termed 'personalised medicine', and is intended to be the future of healthcare.

The DISCIPULUS project has the ambitious task to create a comprehensive roadmap for the realisation of the Digital Patient (DP) initiative, which will enable clinical decisions to be better informed by the predicted outcomes of different treatment options, and allow patients and clinicians to become more pro-active in instituting lifestyle modifications and clinical surveillance for the prevention of diseases.

The Digital Patient Roadmap is one of the top Work Packages (WPs) of the DISCIPULUS project. It will produce the Digital Patient Roadmap, based on both the discourse within the consortium and the consultation process with key stakeholders. It will thereby integrate results from earlier WPs, including identified priority research needs as well as short-, mid- and long-term efforts needed to realise the milestones identified.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, IT professionals	Digital Patient Roadmap	Usage and integration of the DISCIPULUS project's Digital Patient Roadmap	To be discussed and decided in the frames of WP 7, Task 7.1.

3.4 MD Paedigree

MD-Paedigree[8] represents a clinically-driven and strongly VPH-rooted project, where 7 world-renowned clinical centres of excellence pursue improved interoperability of paediatric biomedical information, data and knowledge by developing together a set of reusable and adaptable multi-scale models for more predictive, individualised, effective and safer paediatric healthcare, being scientifically and technologically supported by one of the leading industrial actors in medical applications in Europe operating in conjunction with highly qualified SMEs and some of the most experienced research partners in the VPH community.

MD-Paedigree validates and brings to maturity patient-specific computer-based predictive models of various paediatric diseases, thus increasing their potential acceptance in the clinical and biomedical research environment by making them readily available not only in the form of sustainable models and simulations, but also as newly-defined workflows for personalised predictive medicine at the point of care. These tools can be accessed and used through an innovative model-driven

[7] DISCIPULUS project, http://www.digital-patient.net [November 2013]

[8] MD-Paedigree project, http://www.md-paedigree.eu [November 2013]

infostructure powered by an established digital repository solution able to integrate multimodal health data, entirely focused on paediatrics and conceived of as a specific implementation of the VPH-Share project, planned to be fully interoperable with it and cooperating, through it, also with p-Medicine.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, IT professionals	Computer-based predictive models	Usage and integration of the MD-Paedigree project's computer-based predictive models of various paediatric diseases	To be discussed and decided in the frames of WP 7, Task 7.1.

3.5 REWIRE

REWIRE project[9] proposes to develop, integrate and field test an innovative virtual reality based rehabilitation platform, aimed at allowing patients, discharged from the hospital, to continue intensive rehabilitation at home under remote monitoring by the hospital itself. The main idea is to assemble off the self-components in a robust and reliable way to get a system to be deployed massively at the patients' homes, enabling home-based effective rehabilitation to improve disabilities and functions.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, IT professionals	Virtual reality based rehabilitation platform	Linkage and/or integration of the REWIRE project's virtual reality based rehabilitation platform	To be discussed and decided in the frames of WP 7, Task 7.1.

[9] REWIRE project, http://www.rewire-project.eu [November 2013]

4 Social Media Networks

Social media is the collective of online communications channels dedicated to community-based input, interaction, content-sharing and collaboration. Websites and applications dedicated to forums, microblogging, social networking, social bookmarking, social-curation, and wikis are among the different types of social media. Social networking is the grouping of individuals into specific groups, like small rural communities or a neighbourhood subdivision. The need, of using interconnecting communication technologies, is that the web is filled with millions of individuals who are looking to meet other people, to gather and share first-hand information and experiences, develop friendships, professional alliances, finding employment, business-to-business marketing and even groups sharing information. The architecture of such systems is very well described by Matthew A. Russell[10] where the presented examples include Wikipedia, MySpace, YouTube, Flickr, Del.icio.us, Facebook, Technorati, and many more.

4.1 Collective knowledge: Social Web meets Semantic Web in MyHealthAvatar

Collective intelligence is a vision, one to which information and knowledge is being created and shared from the collaboration, efforts, and competition of many individuals. Tom Gruber states that currently the Social Web is more of a "collected intelligence": the value of these user contributions is in their being collected together and aggregated into community- or domain-specific sites[11]. A *collective knowledge system (*human–computer system) can allow the acquisition of large amounts of human-generated knowledge and information. In MyHealthAvatar the linkage to external social networks and systems involves three major actor: a) external social network systems (commuting infrastructures, system APIs, communications, etc.); b) MyHealthAvatar data collection mechanisms; c) external linkage infrastructures and c) intelligent users able to search and use a social system and provide adequate feedback on system's performance. Today technology enables the generation of collected knowledge systems by making it cheap and easy to *Capture, Store*, *Distribute, Communicate* information synchronously or asynchronously. The Semantic Web[12] is able to strength the role of technology for creating collective social media knowledge systems, by adding structure data and information and by using standards to enable interoperability and sharing.

4.2 Online Social Networking Services

Social networking involves the grouping of individuals or organizations together. While there are a number of social networking websites that focus on particular interests, there are others that do not. The latter often are referred as "traditional" social networking applications and usually have

[10] Matthew A. Russell, Mining the Social Web 2nd Edition: Data Mining Facebook, Twitter, LinkedIn, Google+, GitHub, and More, 2013, O'Reilly Media, ISBN:978-1-4493-8834-8 | ISBN 10:1-4493-8834-5, http://shop.oreilly.com/product/0636920030195.do

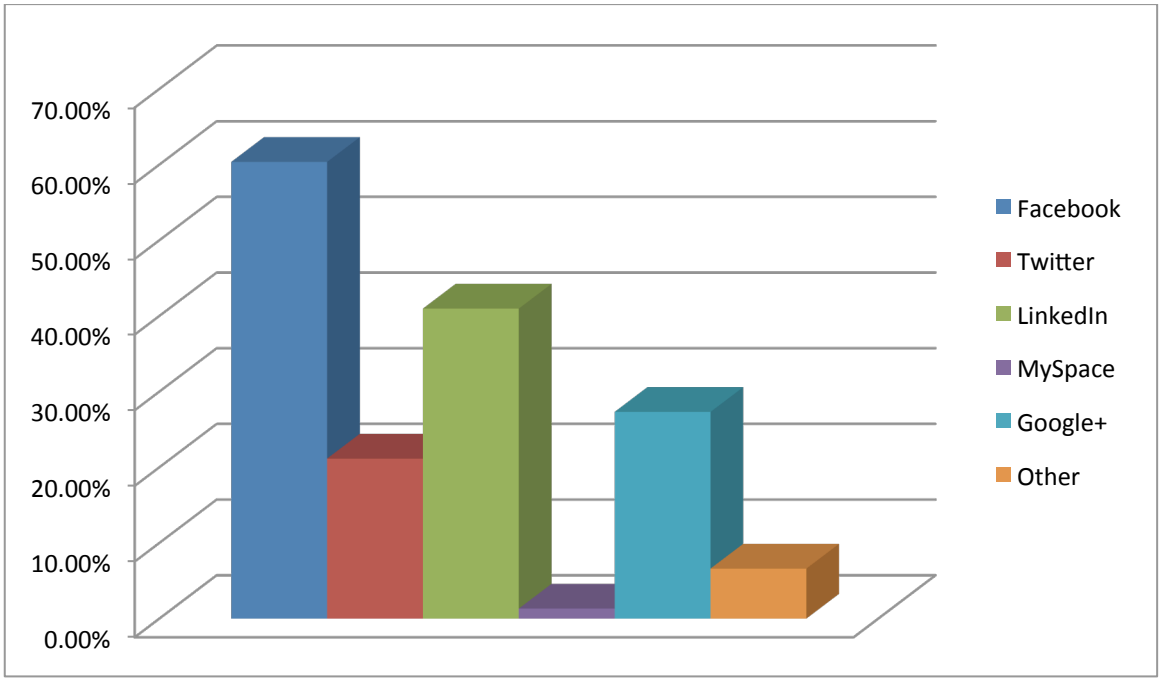
[11] Tom Gruber, Collective knowledge systems: Where the Social Web meets the Semantic Web, Web Semantics: Science, Services and Agents on the World Wide Web, Volume 6, Issue 1, February 2008, Pages 4-13, ISSN 1570-8268, http://dx.doi.org/10.1016/j.websem.2007.11.011.

[12] Tim Berners-Lee, James Hendler, and Ora Lassila: "The Semantic Web". Scientific American Magazine. May 17, 2001.

open memberships. This means that anyone can become a member, no matter what their hobbies, beliefs, views or intense of use are. A social networking platform enables users to create public profiles within that platform and form relationships with other users who access their profile. Social networking platforms can be used to describe community-based Web sites, online discussions forums, chat-rooms and other social spaces online.

According to the Deliverable No. 2.2 "Scenario Based User Needs and Requirements" promising survey results have been collected: all survey respondents appear to be aware about the social networking tools. Despite our initial project focus on Facebook (60,35%) and Twitter (21,15%), the additional reported social networking tools are LinkedIn (useful for enrolment of healthcare provider and research stakeholders) with 40,97% and Google+ (for general public) with 27,31%.

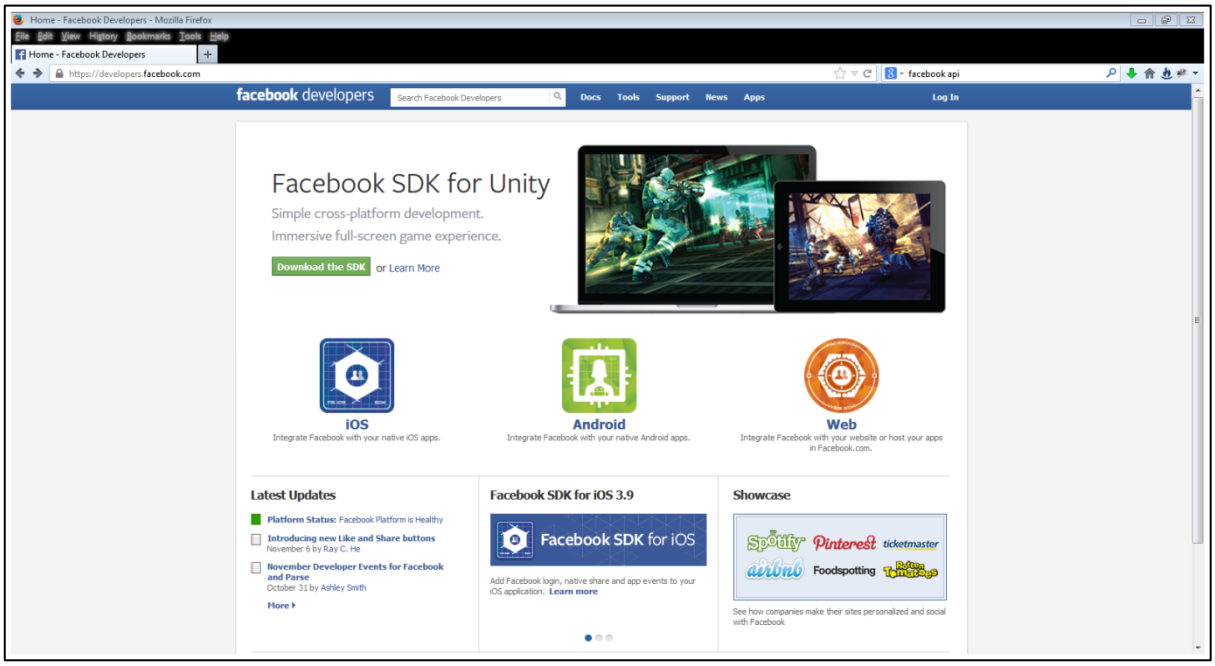
The chart and the table below are the results of the question "Are you a member of any of the following online social networking services?" from the conducted survey, reported in the frames of the Deliverable No. 2.2 "Scenario Based User Needs and Requirements".



Answer	Count	Percentage
Facebook	137	60,35%
Twitter	48	21,15%
LinkedIn	93	40,97%
MySpace	3	1,32%
Google+	62	27,31%
Other	15	6,61%

4.2.1 Facebook

On May 24, 2007 Facebook launched the Facebook Platform[13], which provides a framework for software developers to create applications that interact with core Facebook features. The Facebook Platform is a software environment provided for third-party developers to create their own applications and services that access data in Facebook.



Picture 1. Facebook Developers screenshot (Source: https://developers.facebook.com)

The top Facebook Platform components offered in the frames of Facebook Developers[14] (**Picture 1**) are:

- Social Plugins
  - Like Button - The Like button is the quickest way for people to share content with their friends. A single click on the Like button will 'like' pieces of content on the web and share them on Facebook.
  - Share Button - The Share button lets people add a personalized message to links before sharing on their timeline, in groups, or to their friends via a Facebook Message.
  - Send Button - The Send button lets people privately send content on web site to one or more friends in a Facebook message, to an email address, or share it with a Facebook group.
  - Embedded Posts - Embedded Posts are a simple way to put public posts - by a Page or a person on Facebook - into the content of web site or web page.

[13] Facebook Platform, https://developers.facebook.com [November 2013]

[14] Facebook Developers, https://developers.facebook.com [November 2013]

- Follow Button - The Follow button lets people subscribe to the public updates of others on Facebook.
- Comments - The Comments box lets people comment on content on your site using their Facebook profile and shows this activity to their friends in news feed. It also contains built-in moderation tools and special social relevance ranking.
- Activity Feed - The Activity feed displays the most interesting, recent activity taking place on the web site, using actions (such as likes) by your friends and other people.
- Recommendations Box - The Recommendations feed displays the most recommended content on the web site, using actions (such as likes) by friends and other people.
- Recommendations Bar - The Recommendations bar lets people 'like' content, get recommendations, and share what they're reading with their friends.
- Like Box - The Like Box is a special version of the Like Button designed only for Facebook Pages.
- Registration - The registration plugin lets people easily sign up for the website with their Facebook account. The plugin is a simple iframe that can be dropped into any page. When logged into Facebook, people see a form that's prefilled with their Facebook information, where appropriate.
- Facepile - The Facepile plugin displays the Facebook profile photos of people who have connected with a Facebook page or app.

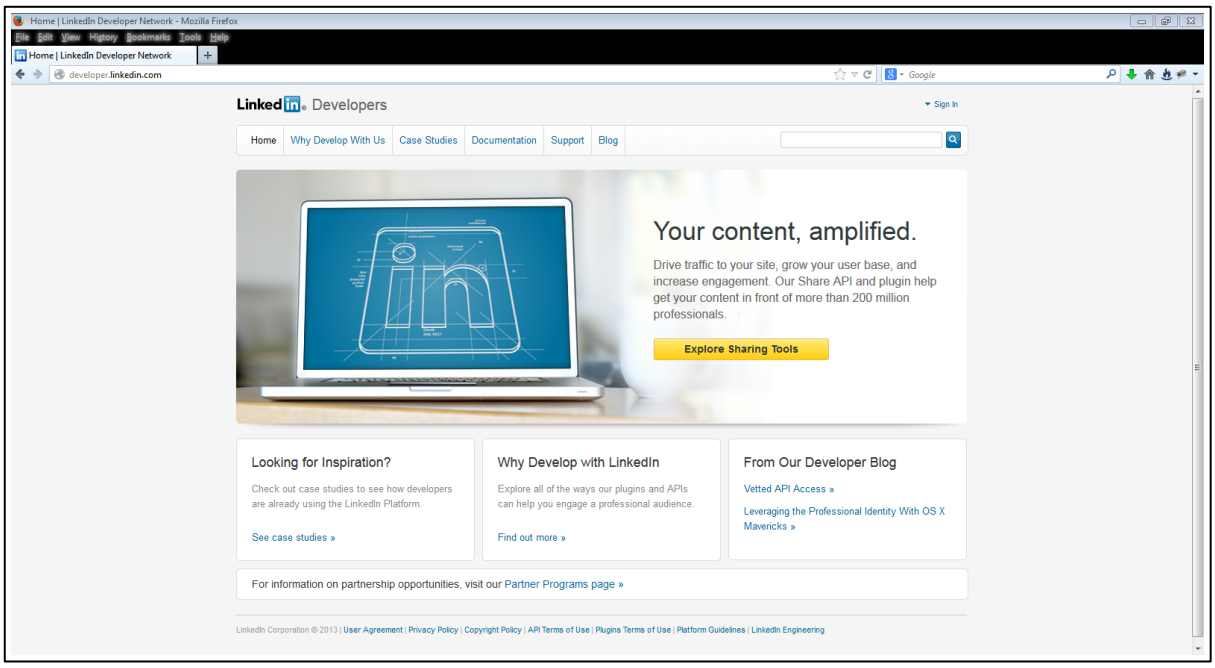
- Login - Facebook Login is a personalized way for people to sign in to the app. iOS, Android, JavaScript, and PHP SDKs are proposed to speed up the registration process and build a functional login system.
- Open Graph - help people tell rich stories on Facebook from any app through a structured, strongly typed API.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, healthcare professionals, general public	Experience and linkage with Facebook • Profile Access • Timeline activity Post/Get/Share	Facebook platform components integration: • Social Plugins • Login • OpenGraph	To be discussed and decided in the frames of WP 7, Task 7.1.

4.2.2 LinkedIn

Founded in 2003, LinkedIn[15] connects the world's professionals with the main goal to make them more productive and successful. With more than 259 million members worldwide, including executives from every Fortune 500 company, LinkedIn is the world's largest professional network on the Internet. The company has a diversified business model with revenue coming from Talent Solutions, Marketing Solutions and Premium Subscriptions products.



Picture 2. LinkedIn Developers screenshot (Source: http://developer.linkedin.com)

The top LinkedIn components offered for developers in the frames of LinkedIn Developers[16] (**Picture 2**) are:

- Share Plugin
- Sign in with LinkedIn
- Share and Social Stream

It is important to mention that LinkedIn is one of the top (40,97%) reported social networking tools used by our survey respondents[17].

End User Needs and Requirements Table

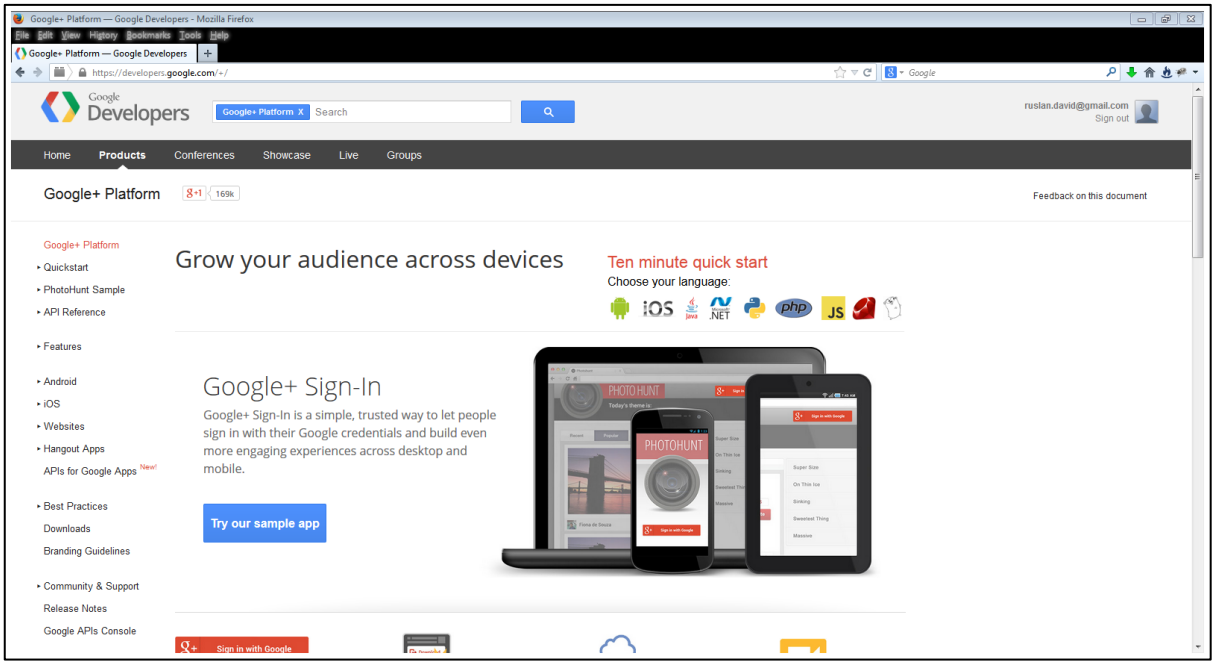
End User(s)	Needs	Requirements	Priority
Researchers,	Experience and linkage	LinkedIn services	To be discussed

[15] LinkedIn, http://www.linkedin.com [November 2013]
[16] LinkedIn Developers, http://developer.linkedin.com [November 2013]
[17] Deliverable No. 2.2 Scenario Based User Needs and Requirements (Survey results)

healthcare professionals, general public	with LinkedIn • Profile Access • Timeline activity Post/Get/Share	integration: • Share Plugin • Sign in with LinkedIn	and decided in the frames of WP 7, Task 7.1.

4.2.3 Google+

Google+ is a social networking service owned and operated by Google Inc. Now, Google+ is reported as the second-largest social networking site in the world after Facebook and it continues to grow; many web developers have begun to incorporate the platform into their social media strategy.



Picture 3. Google+ Platform screenshot (Source: https://developers.google.com/+/)

Our survey respondents reported that Google+ is the on-line social networking service of their choice. (27,31%).

The top Google+ components offered for developers in the frames of Google+ Platform[18] (**Picture 3**) are:

- Simple, secure authentication - Improve registration and sign-in conversion with a fast and secure authentication option for users.
- Interactive posts - Help the users prompt friends to take specific actions in the app from a Google+ post.

[18] Google+ Platform, https://developers.google.com/+/ [November 2013]

- Over-the-air installs - Let web users instantly download and install your app to their Android device.
- Integrated Hangouts - Build collaborative Hangout Apps that bring people together in new ways.
- Profile & social graph access - Show relevant content and connections from circles and profile information.
- Lasting re-engagement - App activities can help to re-engage users when it's relevant in the future.
- Engagement analytics - Tune your performance with stats on downloads, signed-in users, and their activity.
- Google+ plugins - Add plugins to the site to grow the audience, on and off Google+.

End User Needs and Requirements Table

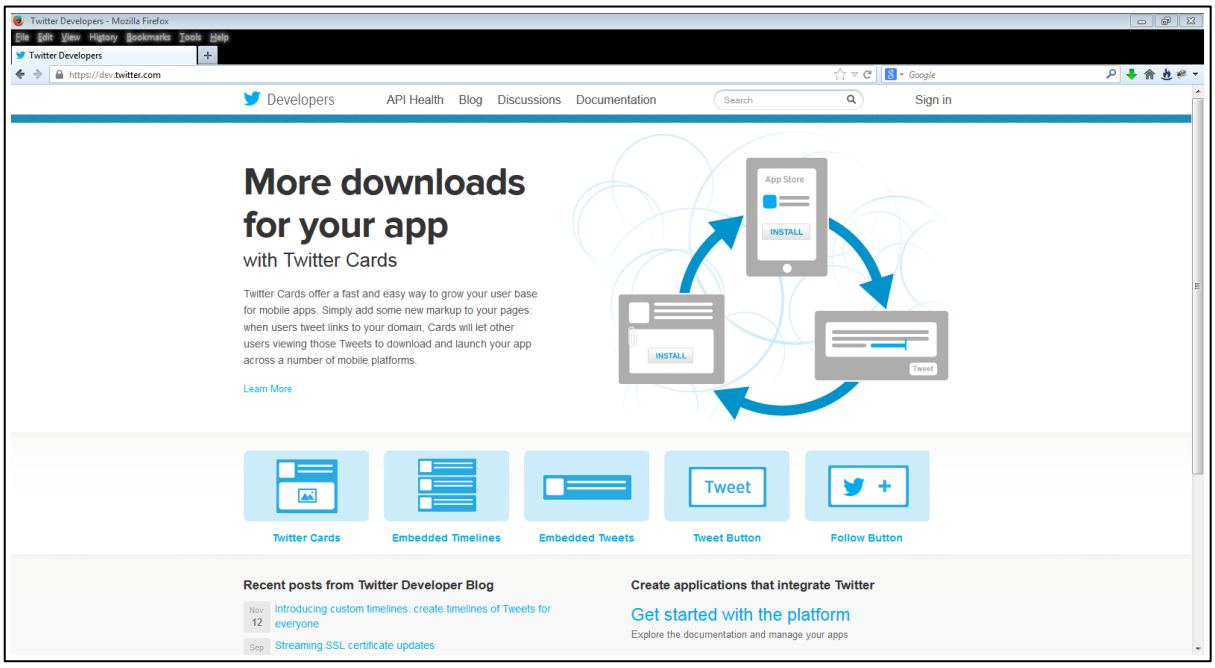
End User(s)	Needs	Requirements	Priority
Researchers, healthcare professionals, general public	Experience and linkage with Google+ • Profile Access • Timeline activity Post/Get/Share	Google+ services integration: • Interactive posts • Integrated Hangouts Google+ plugins	To be discussed and decided in the frames of WP 7, Task 7.1.

4.2.4 Twitter

Twitter[19] is an online social networking and micro-blogging service that enables users to send and read "tweets", which are text messages limited to 140 characters. Registered users can read and post tweets but unregistered users can only read them. Users access Twitter through the website interface, SMS, or mobile device app. Tweets are publicly visible by default, but senders can restrict message delivery to just their followers. Users can tweet via the Twitter website or any compatible external applications/platforms.

Twitter bases its application programming interface (API) off the Representational State Transfer (REST) architecture. REST architecture refers to a collection of network design principles that define resources and ways to address and access data.

[19] Twitter, https://www.twitter.com [November 2013]



Picture 4. Twitter Developers screenshot (Source: https://dev.twitter.com)

The top Twitter components offered for developers in the frames of Twitter Developers[20] (**Picture 4**) are:

- Twitter Cards - Twitter Cards offer a fast and easy way to grow the user base for mobile apps.
- Embedded Timelines - Embeddable timelines allows syndicating any public Twitter timeline to the website with one line of code.
- Embedded Tweets - Embedded Tweets make it possible to take any Tweet and embed it directly in to the content of the article or website.
- Tweet Button - The Tweet Button is a small widget which allows users to easily share the website with their followers.
- Follow Button - The Follow Button is a small widget which allows users to easily follow a Twitter account from any webpage.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, healthcare professionals, general public		Twitter services integration: • Twitter Cards	To be discussed and decided in the frames of WP 7, Task 7.1.

[20] Twitter Developers, https://dev.twitter.com [November 2013]

	• Embedded Timelines • Embedded Tweets • Tweet Button • Follow Button

4.3 Personal Health Social Networking Services

A longitudinal health record containing a patient's medical history, usually named Personal Health Record (PHR), holds the potential to transform healthcare by providing a complete set of patient managed information. We presented in the frames of the Deliverable 2.1[21] a collection of PHR related tools and services, most of them are accessible on-line and could be further explored, some could serve as a technological background for MHA platform.

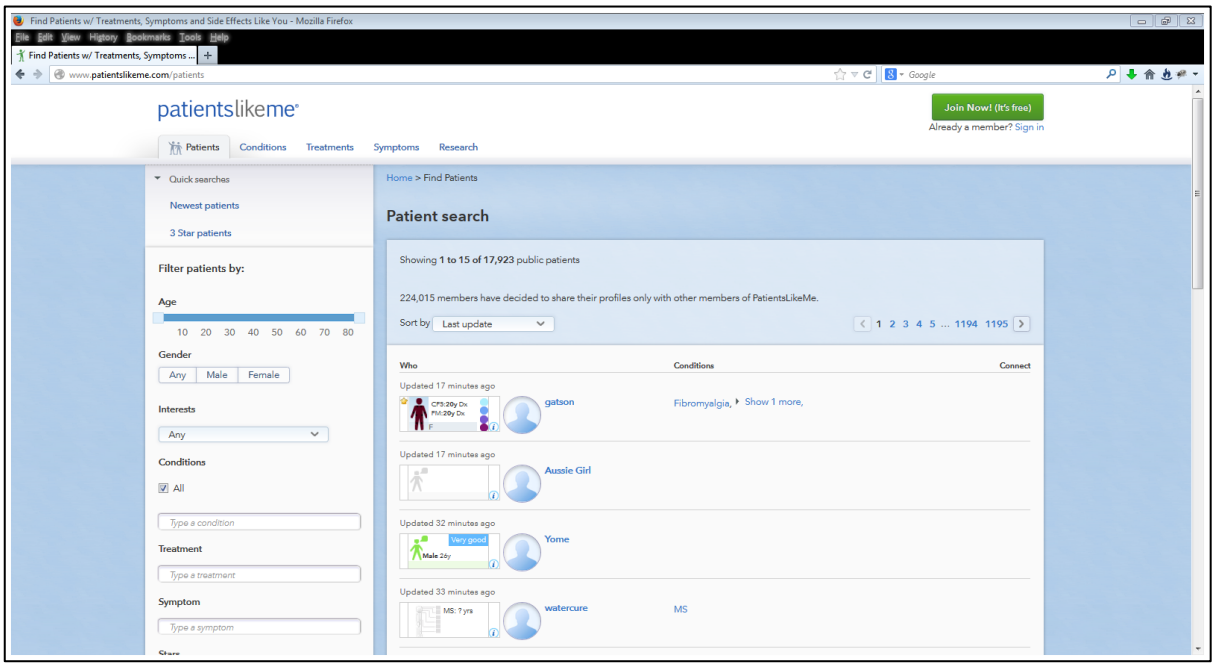
Personal Health Social Networking Services could be described as platforms with the functionalities related to a social networking service in joint linkage with the functionalities of the patient health record system.

4.3.1 PatientsLikeMe

PatientsLikeMe®[22] is a patient network that aims to improve lives and a real-time research platform that aims to advance medicine. Through the network, patients connect with others who have the same disease or condition and track and share their own experiences. In the process, they generate data about the real-world nature of disease that help researchers, pharmaceutical companies, regulators, providers, and non-profits organisations develop more effective products, services and care. PatientsLikeMe is reported by the owners as a trusted source for real-world disease information and a clinically robust resource that has published more than 35 peer-reviewed research studies.

[21] Deliverable No. 2.1 State of the art review related to the MyHealthAvatar environment

[22] PatientsLikeMe®, https://www.patientslikeme.com [November 2013]



Picture 5. PatientsLikeMe Patients page screenshot (Source: http://www.patientslikeme.com/patients)

The business model behind PatientsLikeMe platform (**Picture 5**) is to collect and sell patient's information. The official web site states:

"We create partnerships between you, our patients, and the companies that are developing products to help you. To do that, we take the information you entrust to us and sell it to the companies that can use that data to improve or understand products or the disease market. The personally identifiable information you share upon joining the site (like your name or contact information) is considered restricted and therefore not shared with partners. The data and text you enter in and around the shared parts of the site (e.g., on your profile, in the forum, symptom or treatment reports) may be shared or sold in aggregate to partners."

End User Needs and Requirements Table

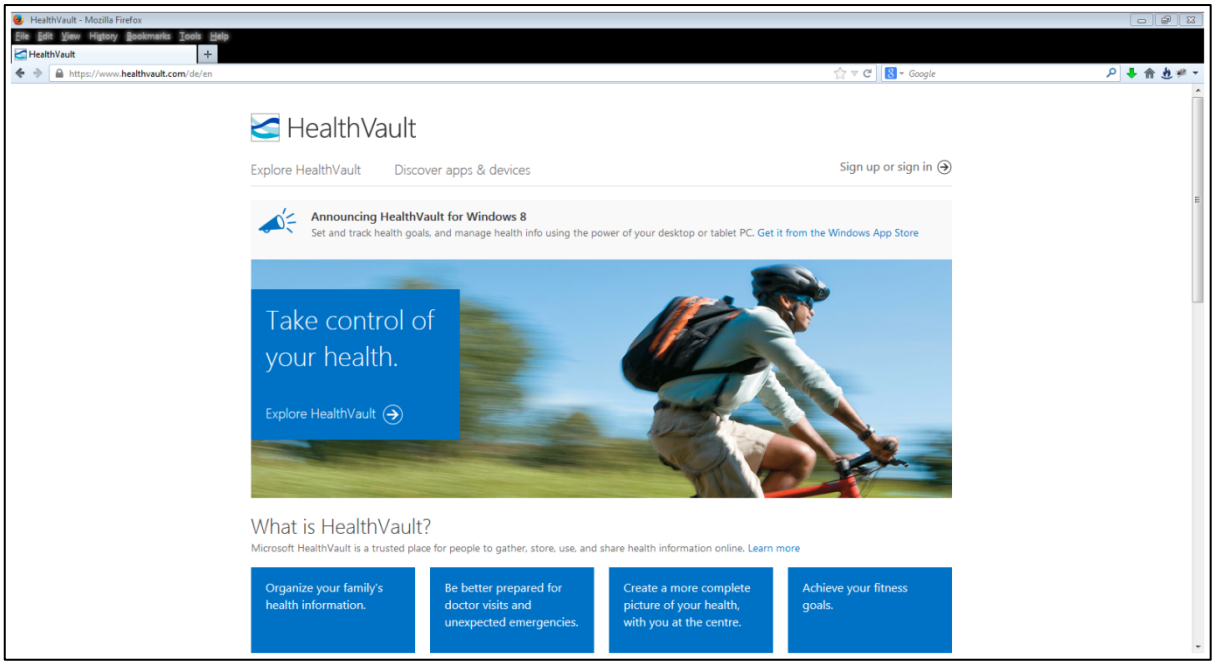
End User(s)	Needs	Requirements	Priority
General public, patients	PatientsLikeMe health data import, export	To identify the tools and services able to import/export health data	To be discussed and decided in the frames of WP 7, Task 7.1.

4.3.2 Microsoft HealthVault

Microsoft HealthVault[23] is a web-based PHR platform able to store, display and transfer health-related data; and store and retrieve medical images. Started in October 2007, the website addresses a wide range of end-users:

- Individuals
- Healthcare providers
- Solution providers
- Developers

In June 2010, Microsoft HealthVault (**Picture 6**) was launched in the UK,[5] the website is accessible at www.healthvault.co.uk



Picture 6. Microsoft HealthVault screenshot (Source: https://www.healthvault.com)

For '**Individuals**' HealthVault is presented as *"an online service that lets you gather, store, use and share health information for you and your family, putting you in control of your health information."*

HealthVault includes various features that help consumers collect, exchange, view and use their personal health information more easily. For example:

- Adding data to HealthVault records by:
  - direct user entry
  - online connection with applications (including web, mobile, email, or data package pickup)

[23] Microsoft HealthVault, https://www.healthvault.com [November 2013]

  - upload from compatible devices (such as pedometers, blood pressure and glucose meters)
- Enabling data access and exchange with people and applications through various methods (for example record sharing, application authorization, email, and access codes)
- Grouping sets of data that are useful for a particular purpose (such as for an emergency medical profile or weight management efforts)
- Graphing collected data (to show trends such as in blood pressure measurements)
- Sending email notifications about records (such as arrival of new data)
- Printing or exporting collected data (for example, to print information for doctor visits or a wallet card)

For '**Healthcare Providers**' HealthVault "*lets patients store health information from many sources, access a range of health and fitness apps, upload data from health and fitness devices, and share health information with those they trust.*"

HealthVault is promoted as a service that can help healthcare providers:

- Improve patient satisfaction through easier communication
- Manage practice overhead by exchanging information (including medical images) with patients electronically
- Implement Meaningful Use patient engagement objectives of the HITECH Act (applies to US only)

Close to other existing functionalities HealthVault is promoting the functionality to give the patient an electronic CCD. "*Almost every EHR now has the ability to save a "Continuity of Care Document" in electronic format. Your patient can upload the document into HealthVault and use it to populate their personal health record.*"

For "**Solution providers**" HealthVault is presented as "*a personal health record technology, HealthVault supports a growing ecosystem of more than 300 connected, user-friendly apps and more than 200 devices. People keep a comprehensive, up-to-date record of their health information in a convenient place where they can view and share it with those they trust. HealthVault also has built-in privacy, security, and user controls that put families in control of their health information.*"

For "**Developers**" HealthVault offers technical description, development basics, SDKs and other services in the frames of the HealthVault Developer Center on MSDN[24]

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
General public, patients	Microsoft HealthVault health data import/export	To identify the tools and services able to import/export health	To be discussed and decided in the frames of WP

[24] HealthVault Developer Center on MSDN, http://msdn.microsoft.com/en-gb/healthvault [October 2013]

	data	7, Task 7.1.

5 Clinical Information Systems

Clinical Information Systems provide a clinical data repository that stores clinical data such as the patient's history of illness and the interactions with care providers. The repository encodes information capable of helping physicians decide about the patient's condition, treatment options, and wellness activities as well as the status of decisions, actions undertaken and other relevant information that could help in performing those actions.

Some of the areas addressed by Clinical Information Systems are:

- Electronic Medical Records (EMRs): this contains information about the patient, from their personal details, such as their name, age, address and sex to details of every aspect of care given by the hospital (from routine visits to major operations) .
- Training and Research: Patient information can be made available to physicians for the purpose of training and research. Data mining of the information stored in databases could provide insights into disease states and how best to manage them.
- Clinical Decision Support: This provides users with the tools to acquire, manipulate, apply and display appropriate information to aid in the making of correct, timely and evidence-based clinical decisions.

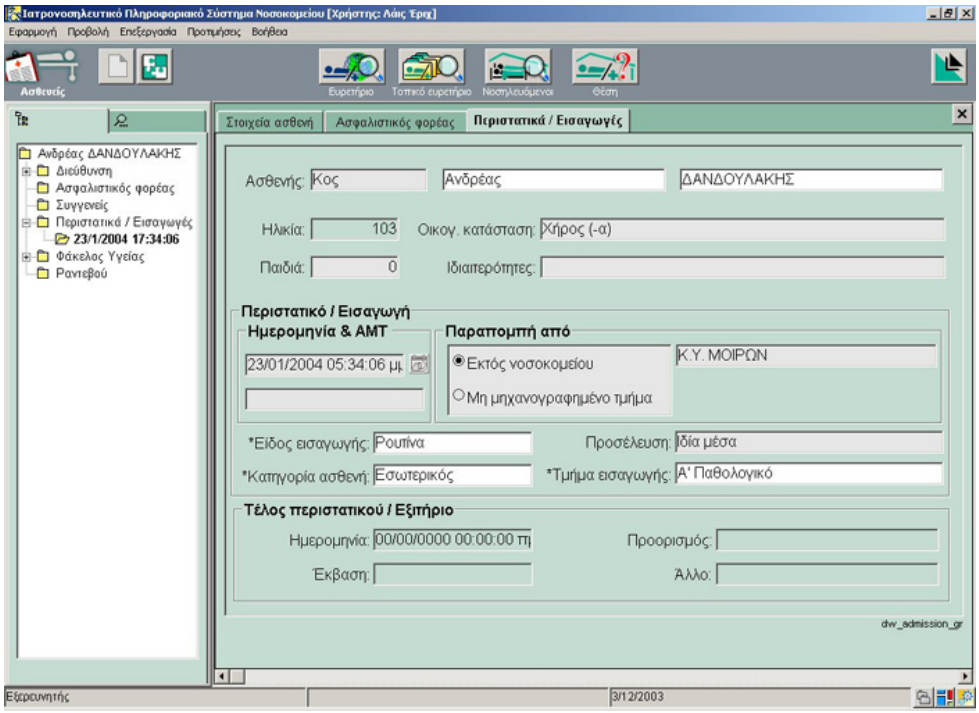
The Clinical Information Systems are typically used inside the Hospitals where a variety of clinical information in medical specialties, like laboratory results and electronic images, are stored and managed. The Integrated Care Solutions from the Computational Medicine Laboratory of ICS-FORTH in an example of such a system that supports the development of clinical information systems to be used in hospitals, Primary Care Centers and other smaller healthcare-providing units. Obtima is also an example of a Clinical Information System used in the context of Clinical Trials as described in the paragraph 3.1.

5.1 Hospital Information System: Integrated Care Solutions (ICS)

Based on an extensible application framework for the development of clinical information systems, ICS provides in a convenient and user-friendly manner the functionality required by doctors, nurses and administrative hospital staff during the various processes and tasks in a hospital, such as inpatient / outpatient management, order processing, reporting, management of nursing activities and health record maintenance. An integrated Coding Schemes Explorer, role-based access control (RBAC), integrated cost registration and billing support belong to the basic characteristics of the system, which is also fully integrated with the standards-based Health Information Infrastructure

Primarily, the system follows a patient-centered approach, while also supporting department-centered and other views wherever required. The intuitive user interface is based on a workbench with different views, including Floor Plan View and Explorer View, which allow access in a context-

sensitive manner to the data and operations supported by the system. ICS, which provides single sign-in with optional SmartCard authentication, relies on the relevant standards for security, message exchange (e.g. HL7, DICOM), information encoding (ICD, SNOP, ATC, etc.) and electronic collaboration (e.g. PIDS, CORBA, COAS). Multilinguality is enabled through appropriate GUI implementation and database design.



Picture 7. A screenshot of the Integrated Care Solutions HIS (Greek interface)

Currently the ICS system has been installed in many of the large hospitals throughout Greece.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
General public, patients	Hospital Information Systems' health data import	To identify the tools and services able to import/export health data	To be discussed and decided in the frames of WP 7, Task 7.1.

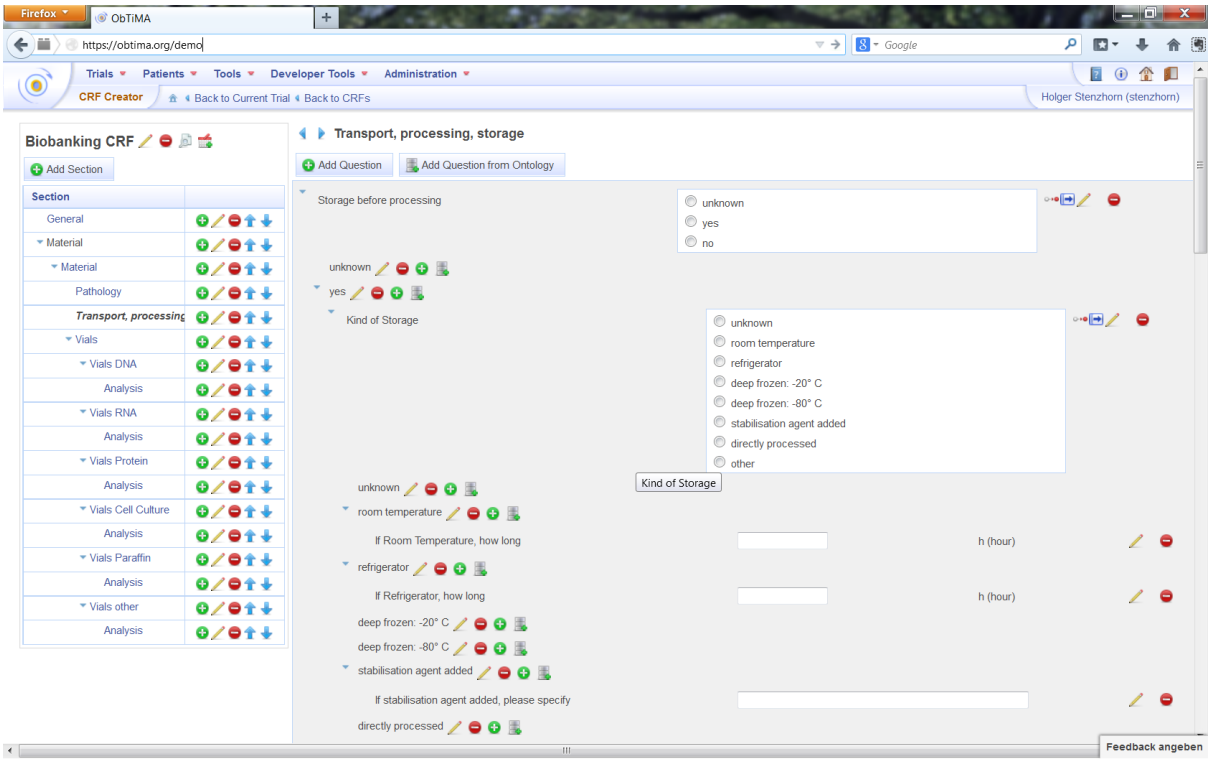
5.2 OBTIMA

ObTiMA is an ontology-based clinical trial management system intended to support clinicians in both designing and conducting clinical trials. The design phase is facilitated by the Trial Builder in which all aspects of a clinical trial can be specified: A trial chairman can define the outline and metadata of a trial in a master protocol to describe, e.g., trial goals or administrative data. He can further setup treatment plans for guiding clinicians through individual patient treatment where events, e.g.,

surgery or chemotherapy, can be defined with all necessary information. In addition, the particular treatment order can be freely setup on a timeline and so can treatment stratifications and randomizations to be applied for a patient. A Case Report Form (CRF) can be assigned to each treatment step to collect documentation data.

The ontology-based creation of CRFs in the Trial Builder is one of ObTiMA's major functionalities. A graphical user interface allows defining content, navigation, and layout of CRFs to capture all patient data during a trial, e.g., medical findings or diagnostic data. The resulting descriptions are based on concepts from the Health Data Ontology Trunk (HDOT) for each CRF item along with metadata, e.g., data type and measurement unit, and are used to setup the trial database.

The user interface makes the underlying aspects of the ontological metadata transparent to users and tries to close the gap between clinical practice and the actual logical representation of ontological concepts. (Even if natural language descriptions are given for concepts, they rarely reflect the needs of clinical perception of reality. Therefore an application-specific, simplified view of the ontology is given showing only its relevant portions in a clinician-friendly way.) If an item has been created based on a concept, its attributes are determined automatically, e.g., label, data type or answer possibilities, but it can be adopted manually.



Picture 8. Creating a CRF in ObTiMA

Since many trials collect similar or equal data, it is possible to store components of or complete CRFs in a repository as templates. When setting-up a clinical trial, appropriate CRF templates can either be directly reused or can be quickly created by composing them from existing CRF components. This

in turn fosters the CRF standardization since CRFs can then readily be compared on the level of single items (through ontological concepts) and also on component level or in their entirety.

The second major functionality is the patient data management system supporting clinicians during a clinical trial. It is automatically setup based on the items defined in the Trial Builder in the design phase. It guides the clinicians through the treatment of the individual patients according to the given treatment plans and provides an easy user interface to fill in the CRFs for a patient (again hiding the actual underlying ontology concepts from the clinician). When the PDMS is set-up, the trial database is automatically derived from the ontology-based CRF definitions. Thus, provided that appropriate rights are given, the database can then also be accessed by other trials or applications through using a semantic mediation service based on the ontology.

ObTiMA itself is composed of different modules. In addition to the above described basic components, a DICOM server and DICOM viewer, a SAE and SUSAR reporting tool and a consultation tool are integrated. These tools are optional to handle images used in clinical trials or to simplify the SAE and SUSAR reporting according to GCP criteria. The consultation tool stores all consultations in a standardized way in the trial database. ObTiMA itself fulfils GCP criteria, including an Audit Trail. Data safety and security are guaranteed as pseudonymization of private data is implemented according to roles and rights assigned to users of ObTiMA. It is of utmost importance that ObTiMA and TOB will be certified for the use within clinical trials.

End User Needs and Requirements Table

End User(s)	Needs	Requirements	Priority
Researchers, healthcare professionals, general public	ObTiMA integration	Implementation of the Use Case/Scenario: Bidirectional linkage to ObTiMA	To be discussed and decided in the frames of WP 7, Task 7.1.

6 Conclusion

This document is in strong linkage with two recently elaborated deliverables:

- Deliverable No. 2.1 "State of the art review related to the MyHealthAvatar environment"
- Deliverable No. 2.2 "Scenario Based User Needs and Requirements"

The content of this document is incorporating the progress and achievements from previous and running EU funded projects (presented in D 2.1) and by taking into account the elaborated Use Case and Scenarios (D 2.2).

User needs and requirements and the linkage to social networks have been analysed and respective networks (Facebook, LinekdIn, Google+, Twitter, PatientsLikeMe, Microsoft HealthVault) are explored via the interfaces dedicated to developers. All required references and the descriptions have been provided.

The concluding remarks are presented in the next paragraph.

6.1 Concluding Table on End-User Needs and Requirements

The concluding table with all identified end user needs and requirements for the linkage to external sources such as social networks and for the collaboration with other existing research projects is presented below. All results are proposed for discussion in the frames of WP 7, Task 7.1 where the final decision will be made.

End User(s)	Needs	Requirements	Priority
Researchers, healthcare professionals	Integrate the results and achievements of the VPH Network of Excellence *(VPH-NoE project)*	Access, integration and usage of the VPH ToolKit elements	To be discussed and decided in the frames of WP 7, Task 7.1.
Researchers, healthcare professionals, general public	ObTiMA integration *(p-medicine Project)*	Implementation of the Use Case/Scenario: Bidirectional linkage to ObTiMA	
All end-users	Data protection and data security framework *(p-medicine Project)*	Usage and integration of the p-medicine project deliverable D5.1 Setting up of the data protection and data security framework	
Researchers, healthcare professionals	3D visualised cancer models *(p-medicine Project)*	Integration of the p-medicine's re-usable clinical trial driven multi-scale cancer models	
Researchers,	3D visualised cancer	Integration of the CHIC clinical	

healthcare professionals	models *(CHIC project)*	trial driven multi-scale cancer models
Researchers, IT professionals	Digital Patient Roadmap (*DISCIPULUS project*)	Usage and integration of the DISCIPULUS project's Digital Patient Roadmap
Researchers, IT professionals	Computer-based predictive models (*MD-Paedigree project*)	Usage and integration of the MD-Paedigree project's computer-based predictive models of various paediatric diseases
Researchers, IT professionals, patients	Virtual reality based rehabilitation platform (*REWIRE project*)	Linkage and/or integration of the REWIRE project's virtual reality based rehabilitation platform
Researchers, healthcare professionals, general public	Experience and linkage with Facebook • Profile Access • Timeline activity Post/Get/Share	Facebook platform components integration: • Social Plugins • Login • OpenGraph
Researchers, healthcare professionals, general public	Experience and linkage with LinkedIn • Profile Access • Timeline activity Post/Get/Share	LinkedIn services integration: • Share Plugin • Sign in with LinkedIn
Researchers, healthcare professionals, general public	Experience and linkage with Google+ • Profile Access • Timeline activity Post/Get/Share	Google+ services integration: • Interactive posts • Integrated Hangouts • Google+ plugins
Researchers, healthcare professionals, general public	Experience and linkage with Twitter • Profile Access • Timeline activity Post/Get/Share	Twitter services integration: • Twitter Cards • Embedded Timelines • Embedded Tweets • Tweet Button

		• Follow Button
General public, patients	PatientsLikeMe health data import, export	To identify the tools and services able to import/export health data
General public, patients	Microsoft HealthVault health data import/export	To identify the tools and services able to import/export health data
General public, patients	Hospital Information Systems' health data import/export	To identify the tools and services able to import/export health data

Appendix 1 – Abbreviations and acronyms

API	Application Programming Interface
ACGT	Advancing Clinico-Genomic Trials
CCD	Continuity of Care Document
CRF	Case Report Form
GCP	Good Clinical Practice
HDOT	Health Data Ontology Trunk
MHA	MyHealthAvatar
MSDN	Microsoft Developer Network
PDMS	Patient Data Management System
PHR	Personal Health Record
REST	Representational State Transfer
SDK	Software Development Kit
SMS	Short Message Service
VPH	Virtual Physiological Human
TOB	Trial Outline Builder
VPH-NoE	VPH Network of Excellence