



MyHealthAvatar Newsletter

MyHealthAvatar

Issue 2 - January 2015

Editorial

by Prof. Feng Dong, MyHealthAvatar coordinator

We have been 22 months into MyHealthAvatar.

Overall, it has been a very exciting experience in the work of MyHealthAvatar with significant progresses in the last few months. The silent trend of patient empowerment has greatly influenced the project. The consortium strongly believes that providing a pleasant user experience is the key to success in terms of engaging the targeted end-users. Hence we have cast our focus on user experience, aiming at a range of functionalities that facilitate the users in uploading and managing their data in the MyHealthAvatar platform. These include:

- Some of the latest self-monitoring sensors have been integrated into the platform, allowing the users to save their data in the platform by simply pressing a single button;
- Personal health profiles are summarized and presented to the users on the dashboard to raise self-awareness of their health;
- Daily activities, such as walking, running, transport and their summaries, such as step counts, walking distance, can be accessed

through diary and time-line based visualization. The users can click on any days in the diary to review their activities and movements on a geographical map. They can also use the time-line to show health-related events at multiple levels of details. The diary can also be used to schedule your plans ahead.

- The functionality of linking to social media enables the users to publish their health-related stories in social media such as Twitter.

Meanwhile, many new functionalities are on the way in the next version of the platform, allowing for self-monitoring of a wider variety of activities such as sleeping, diet; supporting activity planning and remaindering; and enabling health status prediction and risk analysis.

Use case selection has been another focus of the project. Through careful considerations by the consortium members, 4 high-end use cases have been selected to demonstrate the wide variety of usage of the platform: the preDiabetes case will show the contribution of the platform to the patient empowerment in long-term

disease management; the congestive heart failure and osteoarthritis cases will demonstrate how the data in the platform can serve external healthcare services and applications; and the Nephroblastoma case will show the value of the MyHealthAvatar data in clinical research.

Significant efforts have also been paid towards outreach activities. We have invited two external projects to participate in the trial of the MyHealthAvatar platform; we have presented our work to audience with a wide variety of backgrounds including medical professionals, patient groups, policy makers, social science researchers, lawyers and business entrepreneurs; we have issued invitations to many of the potential beneficiaries to use the platform and we are expecting their feedbacks to further improve the platform; a MyHealthAvatar promotion video is available from Youtube.

We are welcoming more participants to use the platform and telling us their experience!

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Legal Aspects of MyHealthAvatar

Interview with Prof. Dr. Nikolaus Forgó

First of all, what are some of the common issues in FP7 projects that seek to exploit the knowledge contained in electronic health data?

Though the mining of health data for information has tremendous potential in improving knowledge about diseases, as well as in empowering patients themselves to play a more active role in self-managing their conditions, there are also risks attached to the use of health data without safeguards. These are most clearly the danger of unauthorized access and misuse of sensitive records, constituting a serious breach of patient privacy; secondly, the patient under data protection law at EU and national level, which itself derives from human rights provisions, enjoys a prima facie right to decide what use is made of his data. This means informed consent is normally required wherever possible.

Does MyHealthAvatar raise special issues compared with other FP7 projects regarding the legal framework?

MyHealthAvatar differs from other FP7 projects in many aspects. Thus, whereas MHA deals with a social platform for patients and physicians and the possibility of sharing data in a 'bottom up' manner, other projects more typically have to do with 'top-down' data governance issues, in particular the conditions for health data to be shared within a closed community of researchers.

Nevertheless, there are some applicable overlaps from other projects LUH has been involved in. One key lesson is that for purposes of data protection measures it is important to distinguish between the development, validation and exploitation phases that projects go through, as the requirements for data use frequently differ between these phases.

es.

Sometimes one hears medical researchers and IT specialists helping them to develop new data use applications complain about the high costs in time and logistics of obtaining informed consent, or even claims that patients themselves do not consider this important.

This claim is not consistent with the evidence. It is clear from many surveys that patients do wish to be made aware of the possible uses to which their data may be put, including the risks and implications for them of making their data available in this way. What is true is that there may be practical problems to consent when large amounts of retrospective data have been collected a long time ago. In such cases the law indeed provides for possible data use subject to special safeguards in lieu of consent; however, the onus remains on the researcher to justify why consent was not practical. The starting point in projects like My Health Avatar is that consent is necessary not only in order to protect partners and future platform participants against possible litigation for breaching data protection norms, but also to meet ethical requirements and foster public trust.

Could you please give us an overview of the work you and your team have already undertaken so far?

During the first year, LUH mainly served as a legal helpdesk and created a number of legal guidelines to assist the consortium in dealing with important questions as they arose. For example, we provided advice regarding the legal aspects of cloud computing and analyzed legal issues that could arise in the exploitation phase.

We showed what the general structure of a user information sheet and a Privacy Policy could look like and highlighted key legal points to consider when opening the MHA platform: security concerns, issues surrounding e-consent, and the need for the platform manager to comply with legal duties as the "data controller" under the law.

What are the steps to be taken next?

The next steps will be to create a definition of the ethical and legal framework of MyHealthAvatar and to present a survey on the strengths and weaknesses of the European data protection framework. Concerning the first task, it is crucial to

Prof. Dr. Nikolaus Forgó, born 1968 in Vienna/Austria, studied law in Vienna and Paris. Between 1990 and 2000 he worked as an assistant professor and IT-commissioner at Vienna University's law school. Since 2000 he is full professor for Legal Informatics and IT-Law at the University of Hanover, since 2007 co-head of the Institute for Legal Informatics (www.iri.uni-hannover.de) since 2011 also member of the interdisciplinary research centre L3S (www.l3s.de). Nikolaus Forgó has been constantly doing research, teaching and consulting on all ICT-related legal issues, with particular focus on privacy and data security.



He is regularly consulting public institutions such as the European Commission, the Austrian Parliament, the German Ethics Council and several national Austrian and German ministries on ICT-related issues.



identify solutions relevant to the concrete current development of the project and in terms of the second task, LUH will have to consider the planned changes of the European data protection framework.

The intended adoption of a General Data Protection Regulation would lead to changes that are currently being keenly debated at EU level. It will be LUH's task to monitor and analyze how these legal develop-

ments could affect projects such as MyHealthAvatar that use patient-centered electronic health information.

The Diabetes - EME use case:

by partner BED

Diabetes is the world's fastest growing disease. The personal, social and economic costs of the diabetes epidemic are substantial. Type 2 diabetes in particular is a serious and growing health problem affecting all sectors of the population, and accounts for approximately 85 % of diagnosed cases. Before people develop type 2 diabetes, they usually have "prediabetes", who are classified as people at a high risk of developing diabetes within 10 years. It has been proven that preventing progress from prediabetes to diabetes is possible and powerful. Studies show that people at high risk for diabetes can prevent or delay the onset of the disease through the control of their lifestyles. While some risk factors such as age, race/ethnicity, gender, family history are not modifiable, patients do have control over their weight, unhealthy cholesterol levels, high blood pressure, smoking, sedentary lifestyle, unhealthy diet and high blood glucose level. These include a long-term commitment of dietary change, exercise, regular self-medication, self-monitoring of blood glucose, regular attendance at clinic and for screening programmes.

However, these healthy behaviours are often NOT achieved in practice by prediabetic patients, despite their value being understood by both patients and medical professional. According to many healthcare professionals, the greatest barrier to treating the pre-diabetic patients is their non-compliance with lifestyle recommendations. Evidence suggests

that assisting prediabetic patients in self-management can result in significant gains in health status and reduced risk in progression to diabetes. Patients are motivated by the perceptions of their diabetes over both the short and long term. This includes their views on the likelihood that adverse events will occur, the perceived impact on their everyday life, perceived personal control and perceptions of the effectiveness of preventative strategies.

This demonstration (PDIAB-EME) will be designed for the long-term self-management of healthy citizens, especially for those at the risk of developing diabetes in near future, supporting increased role of patients in prediabetes care. The demonstration will utilise the MyHealthAvatar platform to support and empower patients.

MyHealthAvatar provides a unique platform that empowers normal citizens in terms of supporting their life management and healthy lifestyles. It offers a one-stop service for citizens in terms of data collection, and self-management services, such as monitor, record, and education. The system will support the storage of behaviours and daily activities of citizen. It will function as a supportive environment to empower normal citizens in looking after their own health, raising their self-awareness of any potential risk of developing diseases while encouraging their healthy lifestyles in terms of doing routine daily exercises, stopping smoking and controlling their diet. Therefore, naturally many existing

functionalities in MyHealthAvatar can be directly used for the needs of pre-diabetic care. In addition, we will incorporate tailored services, such as diabetes risk assessment models for pre-diabetic care, which will be used by the users to understand their personal risk of developing diabetes, and the impact of their behaviour and lifestyles towards the risk.

This case will also demonstrate the added value of the MyHealthAvatar platform in emergency cases where the patient could be unconscious. It is imperative that certain critical medical data and the next-of-kin of the patient are known to the attending doctor e.g., if the patient is in a foreign country. Key information such as known allergies to drugs, medications currently being taken, pregnancy status in females, past medical history, insulin resistance in pre-diabetes and the food or beverage recently consumed by the patient can help the doctor to more precisely plan the treatment. Also, the legal consent from the patient or next-of-kin is necessary if the emergency treatment requires administration of general anaesthesia etc. and the patient is unconscious or disorientated. To prevent any such complications, the patient is empowered by the MyHealthAvatar platform to create his unique ID and link it to the next-of-kin and relevant medical data which can be fetched by the attending doctor.

The Nephroblastoma Use Case

by partners ICCS, USAAR

This use case intends to demonstrate the capabilities of the MyHealthAvatar (MHA) platform to assist in formulating personalized strategies for nephroblastoma patients. Nephroblastoma (Wilms') tumour is the most common malignant renal neoplasm in children. This use case is based on the implementation of the Wilms' Oncosimulator (developed by MHA partner ICCS) within the MyHealthAvatar Infrastructure. The Wilms' Oncosimulator is an integrated software system simulating the growth of nephroblastoma tumours and their *in vivo* response to chemotherapeutic modalities within the clinical trials environment aiming to support clinical decision making in the patient individualized context.

The nephroblastoma simulation model is a top-down, predominantly discrete, clinically oriented multiscale model of tumour growth and response to treatment. The model is based on the consideration of a discrete time and space stochastic cellular automaton, representing the tumour region, wherein heterogeneous biological cells, found in various states, reside. The transition rules of the cells from one state to another form the "decision calculators" of the model; these are the evolution and interaction rules between the predefined number of finite states of the model. In this way, several cellular-level biological phenomena reported in literature are incorporated in the model such as cell proliferation, quiescence, differentiation and death (normal and chemotherapy-induced).

The particular use case involves a two-stage process, whereby the end users (clinicians, researchers) first create a so-called "*in silico* profile" of the patient, which they subsequently can be used for deciding on the appropriate personalised pre-

operative chemotherapy treatment schema, using the patient's multiscale clinical data. In the context of MyHealthAvatar project, synthetic patients based on the clinical data collected in the framework of ACGT, p-Medicine and CHIC EU projects and provided by partner USAAR, will be used following pertinent ethical approval.

In the first stage, the available clinical data before and after therapy, which constitute the multiscale clinical profile of the tumour, after the necessary pre-processing, are fed into the nephroblastoma simulation model. This clinical profile includes the response to treatment, which can be measured by tumour volume reduction and percentage of therapy-induced necrosis or remaining vital blastemal cells at the time of surgery. This information, combined with the identification of the histological subtype of the particular tumour and its stage classification, is used for further stratification and individualization of the patient's profile. By integrating insights from the personalized multiscale clinical

profile of the patient, as described above, previous numerical parameter studies and any information that can be gleaned from the experimental and theoretical biology literature, semi-automatic adaptation of the model parameters is conducted by the model developer. The determined model parameter values serve as a patient record for *in silico* tumour characteristics and form the 'in-silico profile' of the patient (fig. 1). Training the model with a patient's data gives a more accurate description of the specific kinetics of disease progression.

In the second stage, the paediatric oncologist user runs a number of experiments *in silico* (= on the computer) simulating the most likely response of the tumour to the most relevant candidate chemotherapeutic schemes. The outcomes of the simulations (predictions) help the oncologist decide the appropriate treatment plan (fig. 2).

The nephroblastoma case provides multiple benefits for modellers and clinicians as well. Utilizing data from



Figure 1: Schematic representation of stage 1 of the nephroblastoma use case: 'In-silico profiling' of patients with Wilms' tumor

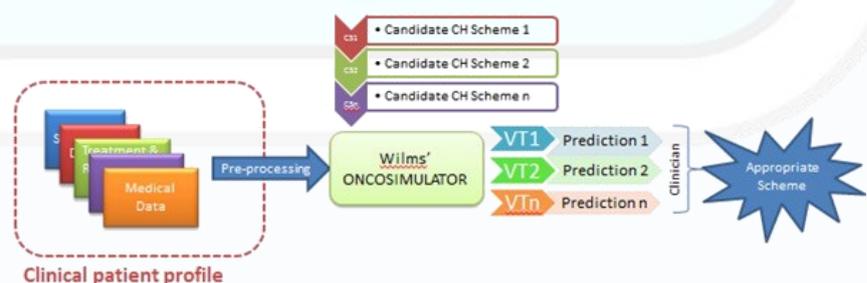


Figure 2: Schematic representation of stage 2 of the nephroblastoma use case: Prediction simulations



SIOP trials provides a reliable reference for both developing and validating *in silico* models. Ultimately, this use case aims at quantitatively predicting the response to preoperative chemotherapy, which would permit to avoid unnecessary treatment in non-responding tumours and apply chemotherapy only to those patients that would benefit most. The entire procedure can also be the basis for a clinical decision support tool for the less experienced clini-

cians. Furthermore, the 'in-silico profile' created in the first stage, could be further used by clinicians as a tool to provide insight into the biological characteristics of a specific tumour, as an input for future use in the same model, as an input for the use in other models (e.g. within the collaborating CHIC project's platform) and as a statistical tool to categorize patients (by associating their clinical and *in silico* profiles) and define ranges of model param-

eter values to guide the process of model adaptation for new patient cases.

The nephroblastoma case will also be used for dissemination and teaching purposes to show the citizen what 'in silico' oncology can provide and to demonstrate parents of children with nephroblastoma how preoperative chemotherapy will shrink the tumour.

News from MyHealthAvatar

- The first version of the **MyHealthAvatar platform** is up and running. It is available on the following link: <http://myhealthavatar.org/mha/>. A Starter Kit can also be found on the project website, on this link: <http://www.myhealthavatar.eu/wp-content/uploads/2014/11/MyHealthAvatar-starter-kit.pdf>
- Partner BED has prepared a **YouTube promotion video** for MyHealthAvatar as part of the dissemination effort. The video can be found on the following link <https://www.youtube.com/watch?v=Izbl4A5xRIA>
- The latest **MyHealthAvatar plenary meeting** took place in Homburg on 18-19 Sept, 2014. Among other issues addressed, the four High-End Clinical Cases were defined (Chronic Heart Failure, Osteoarthritis, Nephroblastoma, Diabetes – Emergency Contact).
- On 3-4 November 2014, the **6th International Advanced Research Workshop on In Silico Oncology and Cancer Investigation – The CHIC Project Workshop**, hosted by partner ICCS, took place in Athens Greece. Prof. Dr. Norbert Graf presented a paper describing the analysis of the MyHealthAvatar Survey. Information about the workshop can be found in the following link: <http://6th-iarwisoci.iccs.ntua.gr/>
- Partner Larkbio participated in **Medicine 2.0**, the annual open, international conference on Web 2.0 applications in health and medicine, also known as the World Congress on Social Networking and Web 2.0 Applications in Medicine, Health, Health Care, and Biomedical Research, which took place on 9-10 October 2014 at Sol Príncipe - Torremolinos, Spain. The MyHealthAvatar project was presented through a paper, the abstract of which is available on the website of the conference: <http://www.medicine20congress.com/ocs/index.php/med/med2014b/paper/view/2757> and a poster presentation by Ziggy Kovacs. The congress was organized and co-sponsored by the Journal of Medical Internet Research, the International Medical Informatics Association, the Centre for Global eHealth Innovation, CHIRAD, and a number of other sponsoring organizations. Its programme can be seen on the following website: <http://www.medicine20congress.com/ocs/index.php/med/med2014b/schedConf/program>
- Partner FORTH participated in the **International Conference on Conceptual Modeling (ER 2014)**, held in Atlanta, USA on 27-29 October 2014, where a paper was presented describing relevant work to MyHealthAvatar. Conference programme can be found at: <http://2014.erconference.org/conference-program/>
- Partner Larkbio participated in **Danube Scientific Conference**, which took place on 19-21 November 2014 at the Hungarian Academy of Sciences, Budapest, Hungary. The MyHealthAvatar project was presented at partner Larkbio's exhibition place by Dr. Zsuzsanna Maros-Szabo. Information about the conference can be found at the following link: <http://danube-epigenetics.weebly.com/>



- Partner LUH's team gave a speech at the "Nacht, die Wissen schafft" ("A Night Out With Science in Scientific November") on 22 November 2014 to present the legal work done by LUH in the European medical research projects to the public. Team members focused on MyHealthAvatar as this project clearly demonstrates the different ethical and legal requirements one has to consider. The MHA promotion video was shown and pamphlets were distributed. Moreover, the audience had the possibility to ask questions and to discuss legal and ethical issues.

Publications Overview

Haridimos Kondylakis, Vassilis Papakonstantinou, Irini Fundulaki, Giorgos Flouris, "e-Consent without Tears", 8th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) 2014 (Submitted - Pending notification)

Haridimos Kondylakis, Lefteris Koumakis, Stefan Rüping, Eleni Kazantzaki, Kostas Marias, Manolis Tsiknakis, "PMIR: A Personal Medical Information Recommender", European Medical Informatics Conference(MIE) 2014

Stavroula G. Giatili and Georgios S. Stamatakos, "In Silico Neuro-Oncology: Simulating Glioblastoma Multiforme (GBM) Growth and Invasion Under Explicitly Treated Neumann Boundary Conditions Imposed by the Skull. Comparing a Homogeneous with an Inhomogeneous Brain Modelling Approach. Clinical Validation Aspects", Virtual Physiological Human Conference 2014. Trondheim, Norway, September 9-12, 2014

Eleni Kolokotroni, Eleftherios Ouzounoglou, Martin Stanulla, Dimitra Dionysiou and Georgios S. Stamatakos, "In Silico Oncology: Developing and Clinically Adapting the Acute Lymphoblastic Leukemia (ALL) Oncosimulator by Exploiting Pathway Based Gene Expression Analysis in the Context of the ALL-BFM 2000 Clinical Study", Virtual Physiological Human Conference 2014. Trondheim, Norway, September 9-12, 2014

Haridimos Kondylakis, Dimitris Plexousakis, Vedran Hrgovic, Robert Woitsch, Marc Premm, Michael Schuele, "Personal eHealth Knowledge Spaces through Models, Agents and Semantics", International Conference on Conceptual Modeling (ER 2014) , pp. 293-297, 2014, Atlanta, USA.

M.Soltaninejad, T. Lambrou, A.Qureshi, N.Allinson, X.Ye, "A Hybrid Method for Haemorrhage, Segmentation in Trauma Brain CT", 18th Annual Conference in Medical Image Understanding and Analysis (MIUA) 2014, London.

Georgia Troullinou, Haridimos Kondylakis, Evangelia Daskalaki, Dimitris Plexousakis, "RDF Digest: A novel platform for summarizing RDF/S Knowledge Bases", World Wide Web Conference 2015 (Submitted)

Spanakis, E.G., Yang, P., Deng, Z., Sakkalis, V., Kafetzopoulos, D., Marias, K., Tsiknakis, M.N., & Dong, F. (2014). "MyHealthAvatar: personalized and empowerment health services through Internet of Things technologies", 4th International Conference on Wireless Mobile Communication and Healthcare, November 3-5, 2014, Athens, Greece

Ruslan David, Feng Dong, Yvonne Braun, Norbert Graf, "MyHealthAvatar Survey: Scenario Based User Needs and Requirements", 6th International Advanced Research Workshop on In Silico Oncology and Cancer Investigation – The CHIC Project Workshop, 3-4 November 2014, Athens, Greece

Upcoming events of interest

MyHealthAvatar Technical Meeting

The next technical meeting will take place at Luton, UK on 22nd & 23rd January 2015

MyHealthAvatar 4th Global Meeting

The 4th Global MyHealthAvatar Meeting will take place at Lincoln, UK on 25th & 26th February 2015



Subscription

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All issues of the newsletter and a form for subscription to the newsletter are available on our website: <http://www.myhealthavatar.eu>

The newsletter can also be requested by contacting Feng.Dong@beds.ac.uk or nikchris@mail.ntua.gr

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