



Project Acronym: **MovingLife**

Project Full Title: **MOBILE eHealth for the VINdication of Global LIFEstyle change and disease management solutions**

Grant Agreement #: **287352**

Funding Scheme: **FP7-ICT-2011-7**

Project website: www.moving-life.eu

D3.2 ANNEX – Vision scenarios in mobile healthcare: Scenario storylines

Deliverable:	D3.2 ANNEX
Title:	Vision scenarios in mobile healthcare: Scenario Storylines
Due date:	N/A
Actual submission date:	17 August 2012
Lead contractor for this deliverable:	IN-JET
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Dissemination Level:	PU

Abstract

This deliverable presents the storylines for the four vision scenarios that were described in D3.2 Vision scenarios in mobile healthcare. The four storylines are based upon the scenario descriptions of four alternative but equally plausible visions about mobile healthcare services and solution in 2025. The present deliverable is intended as a supplement to D3.2 Vision scenarios in mobile healthcare.

Document History

Version	Issue Date	Stage	Content and changes
0.1	07-06-2012	Scenario 1 draft	Bent Grubb Larsen, IN-JET
0.2	27-06-2012	Scenario 1 review and minor changes	Trine F. Sørensen, Helene Udsen, IN-JET
0.3	19-07-2012	Scenario 3 draft	Trine F. Sørensen, IN-JET
0.4	24-07-2012	Scenario 3 review and minor changes	Helene Udsen, IN-JET
0.5	25-07-2012	Scenario 2	Helene Udsen, IN-JET
0.6	13-08-2012	Scenario 4 draft	Trine F. Sørensen, IN-JET
0.7	14-08-2012	Scenario 4 review and minor changes	Helene Udsen, Louise B. Riley, IN-JET
0.8	16-08-2012	Compilation, summary and introduction	Trine F. Sørensen, IN-JET
0.9	16-08-2012	Review and minor corrections	Helene Udsen, IN-JET
1.0	17-08-2012	Complete	Trine F. Sørensen, IN-JET

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1 Executive Summary

This deliverable contains storylines for each of the four vision scenarios that were presented in the deliverable D3.2 Vision scenarios in mobile healthcare. These storylines were developed as recommended by the reviewers during MovingLife's 1st review meeting in April 2012.

The scenarios are based on the Trigger Question: How will mHealth applications and solutions be used in chronic disease management in 2025?

The original environmental context descriptions for each of the four scenarios are repeated in this document in order to present the scenario context and storylines together. Information on the methodology used to create the vision scenarios can be found in D3.1 Workshop report and D3.2 Vision scenarios in mobile healthcare.

The four storylines take the environmental description as their starting point. They describe different daily situations of how users interact with mobile health. The characters in the storylines who interact in various ways include patients suffering from different chronic conditions, their immediate families, friends, nurses, GPs, hospital doctors and other healthcare professionals.

The MovingLife consortium chose to use the scenario "There must be an app for that!" for the gap analysis in WP4. The results from the gap analysis fed into the deliverable D4.1 Consultation document. The scenario is included as background information in the consultation process which is currently taking place. For further information about and participation in the online stakeholder consultation please visit MovingLife's website: http://moving-life.eu/viewpage.php?page_id=15. The consultation is planned to run until end of August 2012.

2 Target audiences

This deliverable is targeted at both the project consortium and external stakeholders. The storylines complement the vision scenarios developed in D3.2 Vision scenarios in mobile healthcare and thus feed into other work packages, particularly WP4 and WP5. The different future visions these four storylines present may also be useful for stakeholders who are involved in the development and implementation of mobile health services and solutions.

3 Introduction

The MovingLife project will deliver roadmaps for technological research, implementation practice and policy support with the aim of accelerating the establishment, acceptance and wide use of mobile eHealth solutions. As a result, the project will provide better understanding of the technology options for defining research policies and of the business and regulatory aspects for both private sector-driven and publicly-funded mHealth services through the thematic roadmaps in socio-economic developments and policy frameworks.

To provide input to the work in WP4 Development of Roadmaps and WP5 Impact Assessment, a Vision Scenario Workshop was held in Brussels on 27 January 2012 and four vision scenarios were developed and presented in D2.3 Vision scenarios in mobile healthcare. The method used to create scenarios is described in D3.1 Workshop report and D3.2 Vision scenarios in mobile healthcare.

The MovingLife consortium chose to focus on one of these scenarios, namely the scenario: There must be an app for that! This scenario was subsequently used in the gap analysis and definition of the roadmaps. The scenario plays an important role in the consultation process which is being carried out at the time of writing.

Originally, the scenarios were intended to be presented in the form of a detailed description of the environmental context for mobile healthcare in 2025. However, at the first review meeting (27 April 2012), reviewers recommended that full storylines were also developed for each of the four scenarios. Seeing that the scenario “There must be an app for that!” was going to be used in the consultation process, this scenario was developed first of all and made available to stakeholders. The scenario can also be found in a separate annex document that has been made available for MovingLife’s stakeholder consultation. This document is available for download on MovingLife’s website (http://moving-life.eu/downloads.php?cat_id=10).

The present deliverable presents the original scenario context description with their accompanying storylines.

4 Scenario 1: There must be an app for that



Healthcare delivery has become digital and mobile; eHealth and mHealth technologies and applications are vital tools for how, when, where and by whom healthcare is delivered.

mHealth is enabled by the existence of wireless networks and mobile platforms that support full interoperability of all mobile technological solutions that fulfil European standard requirements.

Another important hurdle, namely how doctors are reimbursed, has been overcome by the implementation of clearly defined mHealth payment models combined with a “pay for performance” model. Doctors get paid based on the number of different mHealth services they offer and on the basis of how on the number of patients treated using mHealth solutions and/or applications. While there is a distinction between apps prescribed by the doctors and apps that patients download privately, this payment model also compensates doctors when patients present data from their non-prescribed apps during the consultation.

The overall saturation of smartphone and off-the-shelf apps for everything and anything imaginable has also reached the healthcare system and how patients themselves deal with their medical condition. Using health related apps has become a way of life and patients want apps that respond precisely to their individual needs. Mobile apps developers have now become important stakeholders in the healthcare eco-system.

mHealth is not only used to support and improve the care for the individual, it is also employed for public health purposes. Traditional direct targeted Text Messaging for the purpose of general health education and information has been taken a step further. Today, anyone who has downloaded the public health service app on their smartphone will receive an automatic text message informing them of the presence of communicable diseases in the area. The same app allows public health authorities to receive data from users’ smartphone every time the user enters or leaves an affected area.

Patient and clinician reservations and concerns towards the use of mHealth services and application have been overcome by the implementation of trustworthy certifications which are in place across Europe. This makes it simple and easy to verify, even for the patient, whether an application has been approved for medical use. In addition, data protection and data management regulations have been adopted, enabling the use of mHealth services and applications without jeopardizing the protection of personal and medical data.

In medical practice, mobile technologies and applications have become embedded in patient-centred disease management and flexible care models, which have been able to compensate for the diminishing clinical personnel resources. In fact, patients, especially chronic patients who have particularly high needs and requirements concerning continuous care, hardly even perceive or experience the lack of medical staff. On the contrary, patients feel more connected to their doctor and more actively involved in managing their condition when they have to actively use mobile applications to monitor, record, and transmit medical and personal data.

In addition, simple mobile apps make it possible to collect and record other data than simply those directly connected to the condition in question which strengthen the holistic care model approach. The patient’s experience, lifestyle and well-being are all taken under consideration and different apps can provide support for any of these issue. This could be air pollution data for asthmatic patients carrying a GPS-enabled device which records where and when they use their inhaler. The data can then be shared with other users and a map showing “polluted areas” can be generated. In this way,

asthmatic patients can either avoid those particular areas or take their precautions if they have to enter them. In many ways, these types of applications enable citizen-centred surveillance of health risk factors similar to that employed by the state for public health warnings.

While the vast majority of patients readily embrace mHealth services and applications, patients living in remote areas actually do not have a choice. The scarcity of human resources, the deployment of mobile platforms, wireless networks and technological solutions make mHealth the obvious solution to improve the provision of care for people in remote areas. In addition to the traditional features of remote care and monitoring, an increasing number of unskilled health workers cover health needs in remote areas. Mobile applications and platforms support these workers in making skilled decisions and providing treatment and care.

4.1 Scenario Storyline: There must be an app for that!

It is a beautiful spring morning and retired welder John Erik Jensen is preparing to leave the house in order to visit his general practitioner (GP). These visits have over the last couple of years become increasingly infrequent, but John Erik is content with this as it is not a result of less attention to his moderate Chronic Obstructive Pulmonary Disease (COPD), which he himself regards as a condition, not a disease. The infrequency of his visits is owing to the fact that he himself monitors his condition



and has several options of action to choose from before resorting to a face-to-face visit with his GP.

Before leaving the house John Erik has used his tablet computer to access his care-plan which gathers and presents information concerning his health. It has reminded him to take his medicine and of his appointment with his GP. Reviewing his appointment he has added some issues which he intends to debate with his GP. Furthermore, he has reviewed his latest measurements related to COPD and compared them to previous measurements. The plan also

tells him if the areas he will travel through and to hold communicable diseases (more frequent during winter flu season), and it also informs him about the weather which can actually exacerbate his condition. During winter he might have taken a little extra medication to prevent this, but not on this lovely spring morning.

Packing for the trip he puts his tablet in his bag along with two measurement devices, a spirometer and a pulse oximeter. These devices are wirelessly connected to his tablet and smartphone, both of which have access to his cloud-based condition plan. As a result of this he can measure e.g. his lung function if he is subject to worsening during the trip, and have the result uploaded to his plan using either the tablet or the smartphone and review result and recommendation of action immediately. Owing to the certification of measurement devices, tablet, smartphone and cloud providers, he will know in advance that these will work in concordance and have the necessary levels of security measures to protect his data and thus his privacy. As security certification and the legislation behind it is EU-wide, he is free to travel to his beloved Italy and remain under as close monitoring of his condition as he would at home. And as roaming prices became EU-regulated several years ago, he need not worry about transmission cost or finding accessible Wi-Fi networks.



Last month, John Erik downloaded another commercial app which his son, who is a travel guide, recommended to him. The app registers all relevant local information in a geographical area covering between a 5-15 km radius. This includes tourist attractions, hotels, public transport, shopping centres, medical centres etc. but more importantly it automatically gives you a completed route description

based on your current location. John Erik has created a favourites list, so that information (in your chosen language) useful for his conditions is listed first and foremost, such as the nearest pharmacy and medical clinics specialised in patients with COPD. The information includes how to get there, phone numbers and a dictionary list of relevant words and phrases in the local language. As a theatre fan, he also receives information about the nearest theatres and the shows and with one click on his smart phone he can buy tickets instantly.

Should a device fail, his plan can tell him which devices can be used to replace the faulty one. Certification and standardisation reside in his care plan and in the apps used on his tablet and smartphone. This ensures his ability to change app and he can move his condition plan between different healthcare providers, even between public and privately funded ones.

Reviewing his condition plan yesterday evening with his wife Ellen, they discussed the pros and cons of a private healthcare provider. While generally content using the public healthcare system, John

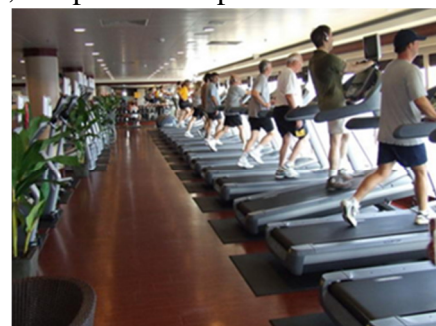


Erik is fascinated by the unified system of some of the private healthcare providers. Several systems for optimising the coordination between primary and secondary sectors of the public health provider have been implemented, but actual unity has not been achieved, which has led to both inconvenience and some miscommunications. Furthermore, the private healthcare providers have a direct economic interest in keeping him out of hospital, owing to the cost of the stay, and will reduce his premium in return for the right to use his data in an anonymised form for clinical research purposes.

Currently the public healthcare system has sought similar permissions to continuously review and improve the clinical pathways underlying the condition plans. John is considering buying an e-patch in order to get a continuous monitoring of his oxygen levels, and actually this would also further reduce his premium with the private healthcare provider. John knows, however, that his GP is also reimbursed based on keeping him out of hospital and using his condition plan and home measurements to monitor him; knowing this reassures John that preventative healthcare is indeed their common goal as the GP also has a direct economic interest in keeping him out of hospital. In the end, John decides to postpone his decision a little longer to see if the coordination and cooperation between public healthcare providers will improve in the near future.

Ellen (6 years his junior) still works part time and she helps him with all aspects of his condition. For this purpose, he has given and renewed explicit consent to allow her full access to his condition plan. He also had to grant his GP access to his plan through the same formal written consent. This consent is subject to renewal at intervals though this seems a formality since John Erik cannot imagine how his GP would be able to participate in monitoring his condition without it. Today, John Erik is seeing his GP to discuss three issues: an incident four days ago in the gym, the private vs. public healthcare provider issue and an idea for a new app for COPD.

John Erik goes to the gym to exercise and thus delay further development of his condition, but a strong social element has proven just as important. He sometimes goes with Ellen, but when she is at work John Erik frequents the gym just the same owing to the jovial atmosphere and comradeship among the attendees of their COPD training group (which they call the “Action Buddies”). The Action Buddies and the exercise plan were offered through his condition plan and the local branch of the Lung-patient organisation. Although tele-training is an option, the Action Buddies prefer meeting in the



flesh; they joke that mHealth technologies have allowed them to stay at home so therefore they really want to get out of the house.

Last Monday John Erik clearly overdid his exercise and ignored warnings from his body, which led to prolonged shortness of breath and discomfort. John Erik and his Action Buddy, Alex, acted to alleviate the incident (rest, measurement, medicine and repetition of measurement) using their smartphone to quickly tap in the symptoms John Erik was experiencing and instants later they got a proposed action plan – both short term and long term actions. Although the incident was worrisome John did not feel the need to also contact the COPD helpline and talk directly to a medical expert for further advice. Also, when his symptoms had been tapped in the systems would have recognised if real-time emergency communication with a medical expert was called for. In this case it did not but recommended that he saw his GP within the next couple of days. Nevertheless, the incident really got John Erik into the e-patch idea entailing continuous oxygen monitoring and it provoked his visit to the GP to discuss this and strategies for avoiding and handling such incidents.

At the GP's office they sit together at the same side of the table to review measurements and medication during the incident in the condition plan as John Erik recounts the event. He was not thoroughly nervous during the incident, as he knew his Action Buddies were both knowledgeable of his condition and experienced, especially Alex. John Erik is commended by his GP for his handling of the situation, but regardless they discuss appropriate strategies and methods of dealing with and preferably avoiding similar incidents in the future.



Then John Erik brings up his idea for an app: Having an e-patch and a GPS enabled device, tracking his walking distance and oxygen saturation would be easy and he could include a competitive element among his Action Buddies with the same app. Several Action Buddies are retired programmers and would be able to do the programming once the concept has been elaborated. It could further be exposed through the Lung-patient organisation. John Erik's GP points out that this app would be a

consumer app, but suggests they go forward and later consider if aspects of the app could align it with certification directives and thus receive approval as a medical app, which could promote it nationally through health-app stores.

As John Erik states leaving the GPs office: "I need to show Alex that I am no weakling! I need to challenge him to cover more kilometres in a week than me, and if there is not an app for that, we will make one!"

5 Scenario 2: Aaarrgh!



This scenario describes a situation where the healthcare system is conservative, neither adapting to patients' individual health needs nor the technological possibilities.

If new care models are even considered they have to be adapted to existing care spaces and healthcare systems, and though numerous eHealth and mHealth technologies and applications are available and interoperable, patients are not actively involved in any decision-making processes regarding their own care.

EU data protection regulations have been put in place as has reliable certification for mobile health services, but a clearly defined payment model for mHealth services is yet to be implemented. Doctors are still typically reimbursed per patient and per visit, and independent of performance and outcomes. Because of this very traditional set-up, face-to-face visits in the doctor's office are still the norm in spite of the abounding opportunities for remote care and communication.

Another reason for this state of affairs is the lack of trust by doctors in measurements taken by the patients themselves, mainly due to the fact that liability remains with the doctors. This again puts a considerable damper on patients' incentive to play an active role in their own healthcare, even though the technology is there to support it, e.g. by the use of mobile devices for ensuring compliance. Patients feel that the motivation they experience when using the many available apps which can often be tailor-made to fit their particular situation perfectly meets with the brick wall of traditional care models in traditional healthcare systems funded by the traditional stakeholders. Regardless of the considerable influence and pressure from patient organisations, new types of stakeholders interested in funding mHealth solutions have met great resistance from a conservative market.

The frustration of higher co-payments without the benefit of the instant medical attention that is technologically achievable is the basis for a less-than-ideal doctor-patient relationship.

5.1 Scenario Storyline: Aaarrgh!

It is ten o'clock; Petra grabs her purse and decamps to the ladies' room. She checks that she is alone – she needs to make an appointment to see her doctor. The line is busy..... 10 minutes later she tries again – still busy. Finally, after seven attempts, she is successful in getting through, only to realise that it is now one minute too late. All she gets is the doctor's answering machine letting her know the timeslot for making appointments. The following day she has more luck; it "only" takes four attempts to get through to the receptionist who sets up an appointment for Thursday the following week. Petra contemplates how much more convenient it would be if it was possible to book visits with the doctor online. For a moment she envies her sister Ivana, who lives in Sweden where this is standard for all general practitioners and most specialists.

Come Thursday, she has to take time off from work to see the doctor. She is a little worried; lately her blood pressure has been too high for no apparent reason. She decided a few years ago to start checking her blood pressure regularly because of her family history; her Father died of a stroke at the age of 58. What further spurred her was the availability of an app for her smartphone that allowed her

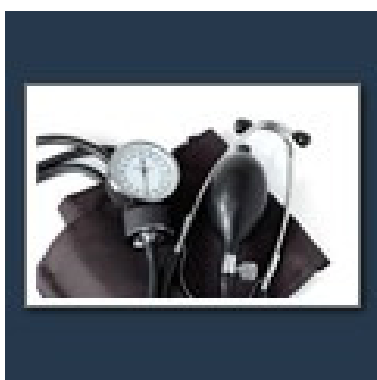
Appointments Online

Appointments Online makes it easy for patients to manage their clinical appointments at the practice themselves. It provides patients with the facility to book & cancel appointments, leave secure messages and request repeat prescriptions.

to collect and save her blood pressure data and retrieve them to show patterns over time. Her plan is to share this information with her doctor.

In the waiting room Petra sees a friend she has met through the local Patients' Organisation for Families of Stroke Victims. It was here that Petra originally learnt of the blood pressure app that is now installed on her smartphone. In a whispered conversation Petra briefly tells Francesca that she intends to make good use of the data she has collected. Francesca cautions her not to get her hopes up, but before she can ask why it is Petra's turn to see Dr Simek.

Inside the doctor's office Petra explains why she has come and makes a move to retrieve her smartphone from her handbag, intending to display her blood pressure data for the doctor's evaluation. But he stops her before she gets that far. He is not familiar with the application that Petra is using, he does not trust his patients to dependably make their own measurements, and at the end of the day treating the patient is his responsibility which is why he insists on relying solely on measurements made under his supervision. Petra protests at first, but soon realises that the doctor is adamant. The nurse is called in, bringing the blood pressure meter.



Petra's blood pressure is indeed high, higher than any of her own measurements, but this could perhaps be attributed to some extent to her annoyance at having been summarily rebuffed and treated as an irresponsible patient who is not fit to be in charge of her own health. She decides on the spot that though it would be technically feasible to enter the new BP data manually and add them to the collection of data already saved via the app on her smartphone, she will probably not do that because she feels certain that these data are not truly representative of her present condition. None-the-less, she makes a mental note of the numbers in case she changes her mind.

Dr Simek goes on with his examination of Petra, determines her weight and height for calculation of her body mass index. Petra does not bother to object, but still thinks this is a waste of time; she already knows that her BMI is well within the normal range.

Dr Simek then tells Petra to ask the receptionist to set up another appointment for blood work to be done and a series of weekly appointments to have her blood pressure measured.

Petra sighs soundlessly at the thought of having to dedicate so much time to physical visits to the surgery. She is definitely not happy with his high-handed doctor-knows-best attitude. But what can she do? It is her experience from talking to friends and colleagues that this is how it is with most doctors in the area, if not in the whole country. The few exceptions are taking advantage of this situation in a different way, insisting that their patients use only specific, so-called 'premium' healthcare apps, of course also at premium prices and incurring unregulated co-payments. However, most doctors are not interested in embracing new technologies or care models, largely due to the fact that reimbursement schemes for anything but face-to-face consultations are more or less non-existent.

The Ministry of Health and doctors' representatives have been negotiating on and off for years to rectify this, but an agreement has not been reached. There is a difference of opinion, apparently insurmountable, as regards the tariff for reimbursement for eHealth and mHealth, compared to the existing tariffs for seeing a patient in the doctor's office.



"How exasperating", thinks Petra; she wishes that no one had come up with the fancy terms 'eHealth' and 'mHealth'. It is all to do with HEALTH under the same umbrella, but as long as different terms

are applied there will also be a tendency to assume different tariffs. The present stand-off, among other issues, is about the size of this difference.

When her next appointments have been set up the receptionist prints out Petra's invoice. She notices that her co-payment has gone up again since her last visit. Same old story: More expense and less satisfaction – and no Brave New World. Aaarrgh!

6 Scenario 3: Something's missing



This scenario reflects a situation where the foundation has been laid for a widespread implementation of mHealth solutions together with innovative care models based on continuity of care and an active patient role. However, technological restraints in terms of privacy, trust and interoperability remain unsolved and therefore the use of mHealth is free of choice instead of the only choice.

The existing mobile platforms and infrastructure networks for mobile phones are capable of fully supporting mHealth solutions and services. Mobile devices that can support health related applications and service are reliable and numerous pilot projects have demonstrated that mHealth services and applications can

improve the efficiency and quality of healthcare delivery. However, there are still some of the more complicated regulatory, technological and end user issues to be resolved before the potential of mHealth can truly benefit medical professionals, patients and society at large.

The healthcare eco-system is based on providing holistic and continuous care to patients. Care models are based on patient-centred disease management and on substituting as much as possible with mHealth solutions and services. Patients with chronic conditions are a particular target group for mHealth because mHealth technologies offer various ways of improving and intensifying the monitoring of these patients. One of the main problems with this group is compliance; patients either simply forget to take their medication or they neglect to do so if they “feel fine”. This patient behaviour is responsible for many serious, but actually avoidable, complications that often require hospitalization.

In theory the care models are based on the premise that mHealth services and solutions should always be offered and if remote care is possible, then face-to-face care is considered obsolete. In practice, however, patients are free to choose if they want remote care and other mHealth services. Moreover, some regulatory and technical issues, such as lack of interoperability and data protection issues, are still unresolved which limits the full potential of mHealth. The result is that the technological possibilities that could greatly improve disease management, including patient compliance, are not being used consistently.

Doctors have also observed that most patients have downloaded health related apps prior to their diagnosis, but that the idea of using these apps as an integral part of their disease management makes many patients worry about protection of privacy. While patients want to share their data with their doctor, they also want to be fully in control as to when, why and how to do so. The lack of data and privacy regulations and policies to cover the new ways of collecting, transferring and storing data in the context of eHealth and mHealth means that patients have no legally recognised guarantee that their personal data will be fully protected, and therefore many opt out of mHealth services.

Medical staff has used mobile devices as a tool for years and having wireless online access to health portals and databases, electronic patient records, medical data etc. is taken for granted. Now that payment models for mHealth services are in place, most medical professionals are very eager to take full advantage of the potentials of mHealth and to offer these services to diminish the burden of increasing numbers of chronic patients. While this group of medical professionals is concerned about the lack of trustworthy certification of mHealth services and applications, those clinicians that are more sceptical use this to blankly refuse to incorporate mHealth in their practice.

6.1 Scenario Storyline: Something's missing

Mrs Lopes, a recently retired school teacher, has travelled by bus the 72 km from her native village of Capileira to at the health clinic in Granada for a general health check. She is not prepared at all when her GP, Doctor Maria Diaz, tells her that her blood pressure and cholesterol is much too high and that she is at high risk of suffering a stroke in the future. Mrs Lopes is prescribed medicine and a home visit is arranged for later in the week. At this home visit, her GP tells her, the nurse will inform her of the self-management scheme which in addition to regular monitoring of her blood pressure will include a diet and exercise plan.



A few days later, Mr and Mrs Lopes sit in their kitchen with the local healthcare assistant Juliana Silva. Although Juliana works for the health clinic in she spends most of her time making house calls in the small villages scattered around in this rugged mountainous region.

After a few initial questions about how Mrs Lopes is feeling, Juliana explains that she is here to develop a detailed care plan for Mrs Lopes with the aim of lowering her blood pressure, and that this plan will require her to take an active role in doing so. She goes on to explain that although the medication is necessary for now the goal is for Mrs Lopes to be able to control her blood pressure without medication but simply by proper diet and exercise.

Juliana pulls out her mobile device and pulls up a questionnaire that will help her establish Mrs Lopes current eating and exercise habits. Once they have completed all the questions the information is automatically analysed and moments later they receive suggestions for a diet and exercise plan complete with illustrations of the provisional effects they will have on Mrs Lopes' blood pressure and general health. The Lopeses are quite impressed by how quick and easy this all seems but at the same time Mrs Lopes in her heart of hearts thinks that it will not be easy to implement all these changes in her life.



Next Juliana shows them how to use the blood pressure meter and how it can transfer data wirelessly to Mrs Lopes' electronic patient record. Juliana has noticed that they both have smartphones and she suggests that Mrs Lopes signs up for the full mHealth service available. This way she can not only self-monitor her blood pressure, but she can also access other mHealth services such as medication reminders, video conferencing with nurses and her GP, and access to online community groups with other patients, which may help with the motivation to implement these lifestyle changes.

However, Mrs Lopes does not like the idea of sharing her data with others; she does not need others to follow her weight loss or blood pressure. Juliana explains to her that she can simply configure the device to hide these data and that she can thus be in complete control of who has access. She goes on to point out that with these mHealth services, Mrs Lopes does not have to travel into the clinic to have her blood pressure taken; she can do it at home and thus much more frequently resulting in a better monitoring. Mrs Lopes looks confused and ask: "What do you mean I don't have to go into the clinic? How will the doctor know what my blood pressure is?" Juliana explains that the application can upload and transmit her data automatically. Granted, it requires her to purchase one of the devices that are interoperable with the health clinic's systems, but they are no more expensive than any of other numerous applications available on the market. Mrs Lopes will not only save time and trouble by not having to go to Granada; neither of them drives and they are therefore dependent on the bus service to Granada which only runs 3 times a day and it is a long and tiresome journey. More importantly, she

will also be able to monitor her condition 24/7. Juliana cannot stress enough how important it is for her to be as much involved and in charge of her condition as possible; studies have shown time and time again that the more involved the patient is the better the condition is controlled.

Mr Lopes then asks about privacy and security issues. Not that he really understands these issues, but their daughter-in-law is doing her PhD on “something to do with applications and security or liability” – he is not exactly sure - and he thinks they should discuss with her before signing up to this full mHealth service. Juliana explains that the service has built-in security features and is completely safe, and that data collected by mHealth services are protected under the general medical data protection laws. But of course, there still no specific laws governing data collected and stored specifically by using mHealth solutions.



In the end, Mrs Lopes resolves to use the blood pressure meter, medication reminder application and an application to automatically store, monitor and analyse her blood pressure, weight and cholesterol measurements. But until they know more about the security and data protection aspect, they will not consent to the automatic transmission of the data. No, she will go in and show her GP those data herself.

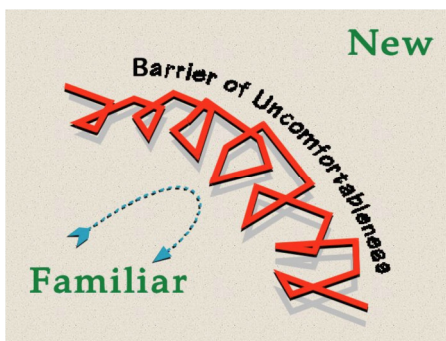
Juliana cannot help but think to herself that partial use of the available mHealth solutions is more frustrating than flat out refusal. She is almost dreading going back to the clinic to inform the doctor that she has yet another chronic patient to attend to in person rather than via remote monitoring. Most of all, she dreads explaining that the main reason for this is the lack of a regulatory framework and patient trust; Her boss, Dr Maria Diaz, is already complaining how these unresolved issues are hindering a full deployment of mHealth services and solutions. As an advocate of mHealth she spends a lot of time at workshops and conferences for medical professionals and time and time again she finds herself at a dead end when some of her clinical colleagues question her medical ethics in using mHealth services and applications when the proper certifications or legal framework are not in place.

Some 10 km away, in the village of Ferreirola, Juliana makes her second home visit that day to Mrs Garcia. Mrs Garcia is an 85 year old widow who suffers from hypertension, diabetes, arthritis and various other conditions all in all making her quite frail. She is still in bed when Juliana arrives at 11 am but her daughter, Carmen, answers the door and lets Juliana in. Mrs Garcia has developed what looks like a bedsore, but it could also be related to her diabetes – Juliana is not sure and takes a photo of it and sends it to the online medical database where it is automatically analysed and compared. Instants later the results come back: it is indeed a bedsore. Juliana receives instructions as how to treat it which he also sends to Carmen’s smartphone so she can attend to it every day.



Carmen shows Juliana the last two months data on her mother’s glucose level, blood pressure, nutrition, weight etc. It is complete with colourful graphs and analysis of the progress thanks to the new App Carmen has installed on her phone. The application she used before turned out not to be compatible with the healthcare system, thus preventing transfer of data between the two. Juliana therefore gave Carmen a list of compatible and interoperable applications. After Mrs Garcia has signed an electronic informed consent form, Juliana transfers the data onto her device which to their relief runs smoothly with this new application, and instants later she receives a detailed analysis and recommendations. The result is not much different from the one Carmen got from her application; the main difference is that via Juliana’s system, the data is also transferred to Mrs Garcia’s electronic patient record which allows the analysis to include Mrs Garcia’s entire medical history. Carmen is pleased and relieved; her initial reservations towards the whole “Apps business”, as she calls it, are much less now that she can see that it works and can be trusted.

7 Scenario 4: No one likes change



In this scenario mobile technologies and applications have not yet met the criteria which need to be fulfilled for a widespread, acceptable and formal use of the technologies in healthcare delivery. As a result it has not been possible to implement the technological developments and potentials with healthcare systems in a revolutionary way. This is due to technological restrictions as well as societal hesitation. Society has not been able to adapt to the changes mHealth represents for all the stakeholders in the healthcare system and there is an unwillingness to implement technological progress and change healthcare models

accordingly.

The use of smartphone and apps is widespread and the mobile networks are reliable and able to support the steady increased traffic and transmission of data. However, privacy and data protection issues prevent authorities and governments from using the data constructively. One example is the recent global bird flu outbreak which led to an EU proposal to use eHealth technologies for monitoring of communicable diseases and use mobile applications to map the movement of persons who have been in contact with infected areas. The proposal was rejected on grounds of privacy and data protection issues, particularly in the light of recent incidents where medical data was bought by a 3rd party and used for commercial purposes.

The distrust in mHealth technologies is also reflected in the lack of use by doctors as well as patients.

Despite the popularity of off-the-shelf apps including health related apps, trial pilots using these applications have shown that patients do not become more actively engaged in their own healthcare. Part of the explanation for this is that doctors do not trust the measurements that patients do at home using mobile applications. In addition, doctors especially do not want to rely or base their treatment on patients' readings because they are still ultimately liable if something goes wrong due to incorrect data. Another reason is that many patients have experienced problems with connecting their device or application to the healthcare platform because of the lack of full interoperability problems. Basically, each different service would require a specific device thus making it impossible to change service provider or service type without also changing the device.

But perhaps the most influential barrier to the deployment and implementation of mHealth services and applications is quite simply the question of money! Doctors are expected to adopt mHealth but as these services do not fall into any existing category, there is simply no way of claiming payment for offering mHealth services. Assumptions that the steady increase of the number of chronic patients GPs must provide care for would encourage the uptake of eHealth and mHealth technologies to provide better and remote monitoring, support medical compliance and self-management have simply proved wrong because of the lack of payment models and other incentives such as payment for performance where keeping a chronic patient out of hospital would activate a bonus to the GP while re-admission would result in a reduction in fee.

While there is an overall demand for flexible and holistic care models and a continuous care process, the demand remains unmet. The potential of mHealth to set new standards for care has been deflated by arguments that mHealth services and application defragment the care process because they change the traditional care delivery path.

7.1 Scenario Storyline: No one likes change

Robert is riding the train on his way home from work. To kill time he is browsing the app store on his mobile phone. He's looking for an easy-to-use app that can help manage his 8 year old son's asthma. He finds one that offers a list of common asthma medications, common asthma triggers to avoid, and a graphing tool to show how users' asthma levels measure against "normal" levels. Also, the app has an alert included which reminds Lucas to take his preventive medication – an excellent service since many of Lucas' attacks has been due to non-compliance. The app appears good and is relatively cheap so he downloads it instantly and looks forward to trying it out with Lucas. Briefly he worries if the app may be on the cheap side, because the collected data are not safe. Recently incidents of misuse have been in the news concerning the sale of health data to third parties without permission. But that involved other types of apps, and Robert finds it less likely that asthma data can be misused. And he is keen to try anything that may make Lucas' life a little easier.



Like most boys his age, Lucas is quite the confident and able mobile app user. He already has a number of interactive tools and games on his phone to help him understand and cope with his severe asthma. In the last year, Lucas has had 8 serious asthma attacks and his parents are becoming desperate to find some way of controlling his asthma better.

A few weeks later Lucas' mom Marie receives a call at work. Lucas has had a serious asthma attack during a school trip to the national museum. His teacher has called the paramedics and they are on their way. Marie drops everything and drives to the emergency room where they are taking Lucas. When she arrives, he has already been attended by the doctors and is feeling better. Her husband arrives a few minutes later, and together they sit down with the doctor who has attended Lucas.

The doctor explains what has happened and ensures them that Lucas will be just fine and that he can probably go home in a few hours. Marie asks the doctor why this keeps happening and if there isn't something – anything – they can do to improve Lucas' asthma? The doctor shakes his head and tells them that, as they already know, asthma can't be cured but of course there are different precautions they can take to minimise the risk of attacks. Marie sighs. She has heard all this before and she can't see how they could take any more precautions than they already take. She feels that Lucas is one stop short of living in a plastic bubble and she just can't bear to restrict his life any more than it already is. She just wants her son be a normal active 8 year old boy.



Robert looks at her and says: "What about this new app?" Marie can't believe her ears. She simply doesn't understand why or how her husband is so keen on these apps; they are toys, not medicine. But Robert starts to explain the app to the doctor. They have only been using it for a few weeks but Robert thinks it has great potential as a tool for preventing future asthma attacks and as a general monitoring tool for Lucas' asthma. The doctor tells them that Lucas should continue to use the app "by all means" and that the data might actually be quite useful from a medical perspective to understand how Lucas' asthma reacts. "But legally I am not allowed to base any medical decisions or treatment on it", he says and Marie shoots Robert a look that says "I told you so". Their GP has said the same thing. The doctor continues: "Actually, my neighbour uses the same app and I think it's one of the best ones on the market but it's not compatible with our system here at the hospital, so even if we wanted to include the data we would have to enter them manually and we simply don't have the resources to do so".

At dinner that night, Marie and Robert are sharing their frustrations over the fact that the hospital staff would not even consider looking at Lucas' asthma level measurements just because they were

collected by a non-prescribed health app. Their frustration is only strengthened by the fact that their GP has admitted that the app could be a very useful tool for managing Lucas' asthma but that since the GP practice doesn't offer mHealth services he as their GP cannot include data from this app when treating Lucas. Their GP had gone on and on about how these types of apps could never replace proper and personal medical attendance or care plans and that it was not just for medical and professional reasons but also ethical concerns that they wouldn't adopt mHealth services. "It would be unethical of me not to be fully responsible and liable for the care and treatment of my patients and even if I prescribe the use of a healthcare app to help manage Lucas' asthma, or any other chronic condition for that matter, legally I am not liable for the use or care resulting from this app. And in my experience, patients quickly lose interest in using these apps", she had explained then. No wonder Robert had thought at times that it was pointless to use the app when your doctor tells you that he then cannot be responsible for your care and refuses to include the data in personalising your care plan. Robert was sure, though, that ethical concerns weren't the only explanation. After all, a GP practice was a business too.

"We ought to find a GP practice that does offer mHealth services", Marie says. "Well, in that case we may need to move to another planet where reimbursement for mHealth services is in place", Robert states dryly. Robert and Marie know all too well from a friend of theirs, who works in the financial department at the healthcare ministry, that the economics of mHealth is a huge problem; GPs have no formal way of claiming payment for providing mHealth services and so the big question is "why should they?".

