

FOREWORD

This is a summary of a White Paper¹ that aims at providing a baseline for the planning of R&D activities that could be supported in the 8th Framework Program of the European Commission².

In a nutshell, we propose to create a move towards a considered approach to “Engineer Awareness^{TM,3}” in individuals. Instead of “compliant patients” we propose to focus on R&D of how individuals are enabled to act responsibly in managing their health and wellbeing through education, training and ICT enabled services.

The project has been funded by the European Commission in the 4th ICT Call of the 7th FP as a Specific Support Action with 12 month duration (Dec '09 – Nov '10). The partners have jointly contributed to the results. The project had an Advisory Panel and organized three workshops to discuss and consult with outside experts.

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¹ The White Paper and all project deliverables can be downloaded from www.preve-eu.org.

² In fact, the proposed research agenda is now included into the 10th Call of the ICT program of the European Commission as task 5.1.a). The Call closes 15.1.2013.

³ Engineering AwarenessTM is a trademark owned by Ospedale San Raffaele (a partner of PREVE).

SUMMARY

It has been estimated that 77% of the disease burden in Europe is accounted for by disorders related to lifestyle. If people would maintain healthy lifestyles, 90% of type II diabetes, 80% of coronary heart disease, and 70% of stroke and colon cancer could be prevented. Most of us know what a healthy lifestyle is. The problem, unfortunately, seems to be that this knowledge evidently is not enough for the average citizen to become aware and to proactively take on the responsibility of managing one’s health.

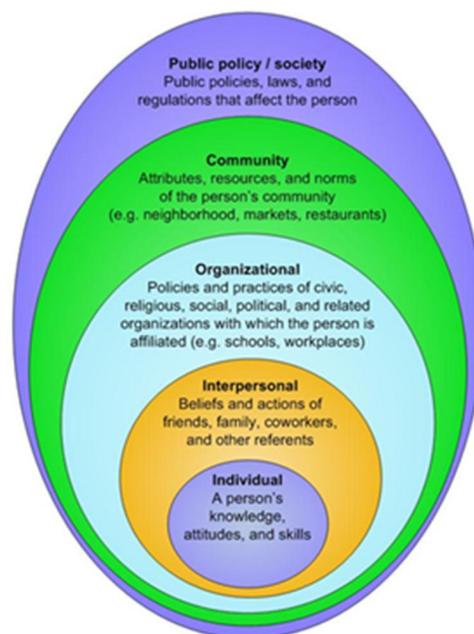
We know that to prevent chronic conditions and diseases we should *exercise regularly, eat healthy, control our weight, sleep enough, manage stress, not smoke and use alcohol only moderately*. We cannot change our inherited genes (at least not yet). Similarly, we cannot alone change the environment (such as accidents, work conditions etc.). For that community a/o society level actions are needed.

These considerations led to the definition of PREVE’s objective as; *what research is needed to create ICT enabled solutions that improve people’s ability to be responsible for their health (“responsibility with response ability”)?*

CO-PRODUCTION OF HEALTH – THE JOB TO BE DONE

People make health related decisions many times a day (24/7). The primary task in PREVE was to understand how people can be supported in their daily routines by ICT enabled services to manage their health, in other words; what is *the job to be done*⁴.

We’ve introduced a concept *Citizen as a Co-producer of Health (CPH)* to describe that individuals interact with others in producing health (see figure on the right). These co-producers include family members, friends, school, workplace, food markets, personal trainers, restaurants, media etc. and also, of course, healthcare professionals. It also includes the policies and incentives that are set at community and society level. In the CPH paradigm healthcare professionals are still “in the loop”). But it is the individuals who each day make choices that influence their health and wellbeing.



Consequently, the job to be done is on one hand to provide guidance to individuals when they “navigate their health journeys” i.e. when they interact with their co-producers and make health choices and on the

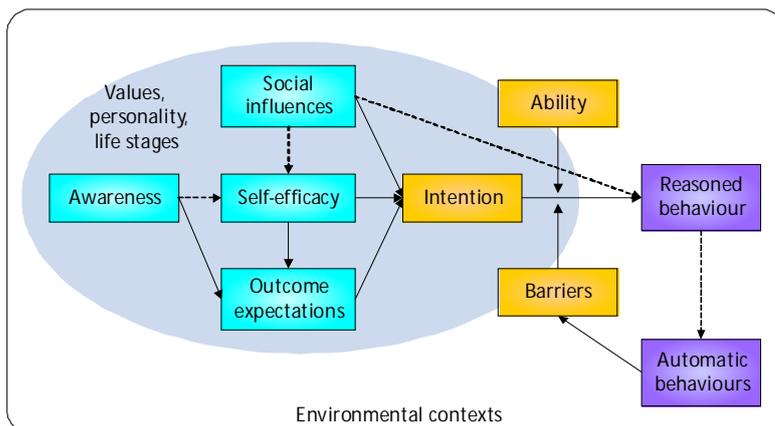
⁴ The term originates from Christensen, C.M., Grossman, J.H and Hwang, J. *The Innovator's Prescription: A Disruptive Solution for Health Care*. McGraw-Hill, 2008.

other hand to adjust the environment so that it makes healthy choices easy to make and maintain over time.

PERSONAL PROFILE – VIRTUAL INDIVIDUAL

In order to support individuals in their health journeys we must understand how people behave. Based on an in-depth analysis of theories of health behaviours we came to the following conclusions:

- People cannot be forced or manipulated to make a lifestyle change. Instead change must be based on *free will*.
- In order for a lifestyle change to take place people must have sufficient awareness, motivation and resources and live in an environment that does not hinder healthy behaviours (see determinants of health behaviour in the figure on the right).
- A personal profile can be constructed that comprises the individual’s clinical risk factors, health behaviours, values, preferences, abilities, intervention goals, demographics etc. We’ve named the personal profile a *Virtual Individual (VI) model*⁵. The model is dynamic and is continuously updated with data from the individual’s actions and the environment.
- Even for similar risk profiles, the optimal way to reduce or overcome risks presents different faces depending on moments of life, different situations or events, present and past. Therefore interventions need to be tailored to match the personal profile of a person.
- People value health differently. On the average health is taken for granted and people are not interested in investing in health if it conflicts with more immediate short term benefits. Only when health is lost people become interested in regaining their health. Therefore it may be necessary to promote short term gains such as general wellbeing and positive experiences (entertainment, games, fun, enjoyment, social networking etc.) and leave the health benefits to the background as additional benefits.



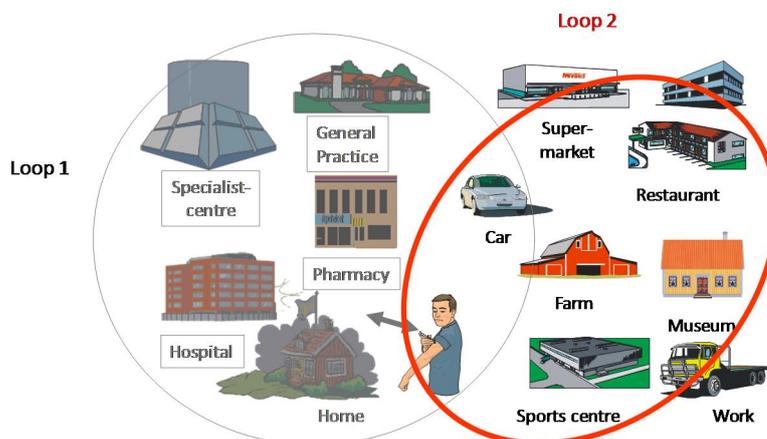
Consequently, health navigators (*HealthGuides*) must be personalized e.g. using the VI model.

RULES OF THE GAME FOR THE HEALTH OUTREACH ECOSYSTEM

The next question was how the CPH ecosystem can be sustained. Based on an in-depth study on how value creation, value networks and business models could be applied in disease prevention we came to the following conclusions:

⁵ The VI model is complementary to the Virtual Physiological Human model. The latter describes the genotype to system level aspects of an individual. The former describes the “soft aspects” that influence our behaviour.

- Technology itself has no value. Instead value is created by the users by using technology enabled services. This also confirmed the previous finding that the support provided from the outside to individuals to manage their lifestyle must be personalized and based on free will.
- The *Rules of the Game* (ROG) of the CPH ecosystem need to be defined. The figure below illustrates this with two loops. Loop 1 represents the traditional healthcare system, where ROG has been defined and refined over the years. Loop 2 is the CPH environment where a new set of ROG is required. In Loop 2 there are two connections to traditional healthcare (1) *HealthGuides* need to be aligned with medical evidence on disease prevention and (2) healthcare professionals are part of the CPH ecosystem.



- Why do we need a new ROG? Why not do it within the current healthcare rules framework? From the healthcare payer perspective this would seem to be the natural way of doing it.

We know that chronic conditions and diseases can to a large extent be prevented. If payers would invest in healthy behaviours that would lead to a decrease in the disease burden and thereby savings in the portion of health expenditure that goes to care for chronic illnesses. Unfortunately the business case is not that simple. There are at least three problems with this argument that need to be solved:

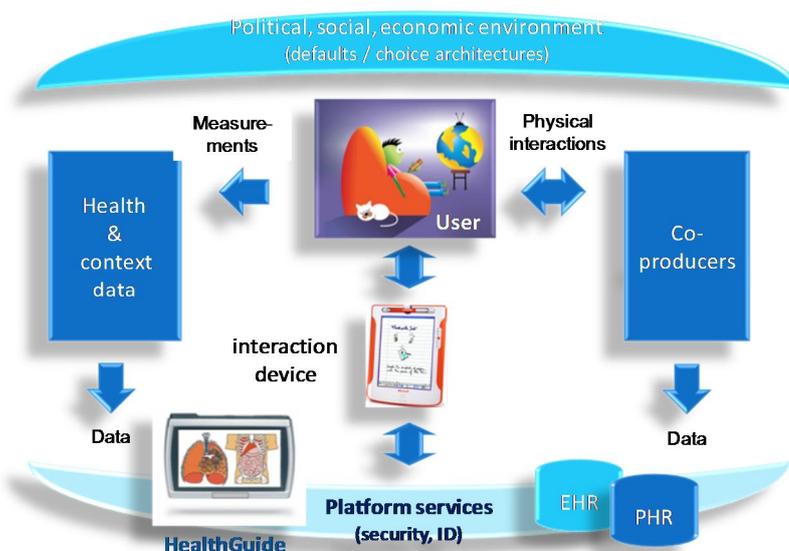
1. Unhealthy behaviours take a long time to manifest as a diagnosed condition. The payers would have to be very patient in waiting for the return of investment. The way medicine and science are progressing today payers are already hard pressed to be able to sustain current healthcare systems.
2. Current healthcare systems are still predominantly illness-centred. Changing its orientation towards prevention and inclusion of the patient into the care loop has been on the agenda now for quite some time but no major changes in the provider incentives or structures have appeared, as yet. The training and skills of healthcare professionals are also more oriented towards caring for the ill rather than coaching healthy and at-risk individuals to manage their lifestyle.
3. Ultimately, it is the individuals who have to make a lifestyle change (and be supported in this by their environment).

Consequently, the Health Outreach ecosystem (i.e. loop 2) as described above cannot be created by healthcare payers (Risk Bearing Organizations, RBO) and providers alone because investing enough healthcare funds in disease prevention is not possible in the present healthcare systems. The way out of this vicious circle is the introduction of new actors. The co-producers can change the way the “prevention game” is played. The Health Outreach ecosystem is a disruptive scenario for the future. It presents an alternative mental model for the prevention game and opens up new avenues for further discussion. With new players bearing the risk, we might finally see some return from prevention.

ICT SUPPORT – HEALTHGUIDES

The next step was to construct a use scenario of ICT enabled disease prevention using the concepts and conclusions discussed above (see figure on the right):

- Users are situated in a supportive environment of healthy behaviours.
- Users interact with their co-producers in their daily activities to jointly create health.
- Users are guided by personalized *HealthGuides* (that deploy the VI model), which monitor their lifestyle and interoperate with Personal Health Records and with Electronic Health Records.



HealthGuides are SW entities, which once instantiated with the user’s VI model provide personalized guidance to users through appropriate channels at opportune moments based on a personalized risk assessment and the (mis-)match between behaviour change goals and users’ decisions and activities. Consequently, *HealthGuides* comprise a number of real time processes that need to be synchronized with each other. This scenario also points to the need of a platform on which *HealthGuides* can be instantiated. In total, the HealthPGS system comprises:

- A *HealthGuide development community* that discovers new evidence, organizes it into behaviour change guidelines and uses the information and knowledge to create new and update existing HealthGuides
- A *PGS-Mall* from where users can download HealthGuides to their devices (e.g. to mobile phones)
- A secure *PGS platform* of common services on which HealthGuide instances can be operated.

ICT RESEARCH DIRECTIONS IN DISEASE PREVENTION

The final task was to identify what research is needed to get the job done, i.e. enable the scenario where users navigate their health journeys with *HealthGuides* and interact with their co-producers in the Health Outreach ecosystem.

The proposed research and stakeholders that need to be engaged in this can be divided into three complementary research tasks as shown in the two tables below. The first lists the tasks and the stakeholders that need to be engaged in each task. The second opens the tasks to a sub task level.

Research task (policy formulation)	Stakeholders
Creating a supportive environment for healthy behaviours.	Citizens, politicians, policy makers at community, society level and EU level

Creating a sustainable Health Outreach ecosystem of users, service providers, co-producers, policy makers and other relevant stakeholders with appropriate ROG for business transactions.	Users, service providers, ICT industry, Healthcare and healthcare professionals, other Health Outreach co-producers, Legislators, Policy makers at member state and EU level
Utilizing ICT to conceptualize, design and build a PGS platform and on which instantiated <i>HealthGuides</i> can engineer awareness and motivation, orchestrate the interactions between users and their co-producers and provide personalized behaviour change support at opportune moments.	“Users and Solution developers” in collaboration with experts in medical evidence, behavior change, user experience, PHS, signal fusion, knowledge based systems, business developers, evaluation, assessment etc.

The two first tasks (environment and ecosystem) cannot be completed by ICT research projects alone. Member states, DG SANCO, DG Enterprise and Industry etc. need to be engaged for policy discussions and formulation. The Lead Market Initiative and the European Innovation Partnership Initiative (especially the Active and Healthy Ageing flagship) need to include disease prevention into their agendas and start to think about initiatives that focus on the “rules the game” in order to enable and incentivize end users to become proactive in managing their health and wellbeing and to move the field from “regulation” to “participation” by all Loop 2 stakeholders.

Although PREVE advocates a Health Outreach ecosystem with its own rules of the game, the role of healthcare systems and healthcare professionals will be central in the creation and nurturing of the ecosystem. Healthcare professionals can influence individuals who are at risk of developing chronic conditions. Similarly, they can coach and support users who need to change their health behaviours. A third issue relates to the content of *HealthGuides*. They need to be aligned with medical evidence on the prevention of chronic diseases. Overall, the participation of the healthcare sector into the ecosystem is of utmost importance. On the other hand, as discussed earlier healthcare systems today are still illness centred. In addition to playing a key role in the Health Outreach ecosystem nurturing healthcare systems should also pay more attention to prevention and management of chronic conditions. This poses a dual challenge to healthcare systems that cuts across all levels from reimbursement and incentives to structures and education and training of healthcare professionals.

<i>Research task</i>	<i>ICT Research Directions in Disease Prevention (sub tasks)</i>
<i>Supportive environment for healthy behaviours</i>	<ul style="list-style-type: none"> ✓ Policies that help to create a supportive environment for healthy behaviours (covering regulations, incentives etc. for physical environment, communities, workplaces, schools etc.). ✓ Health promotion campaigns that target more clearly different user segments combined with the ICT support. ✓ Extended evidence supporting the impact of healthy behaviours on disease burden. ✓ Reengineering current healthcare centred clinical guidelines into citizen centred guidelines that focus on patient responsibility centred supportive life plans, including a strong psychological component focused on behaviour change and motivation. ✓ Validation studies on how ICT can be applied in disease prevention and especially in providing

	personalization and tailored response.
<i>Sustainable Health Outreach ecosystem</i>	<ul style="list-style-type: none"> ✓ Rules of the Game (ethical, legal, incentives, policies, etc.) that enable a sustainable ecosystem focused on providing services for people to manage their lifestyle. ✓ Finding a way for current healthcare providers to work within / with the Health Outreach ecosystem actors. Will this require new structures a/o incentives? Are there needs for re-skilling through training? ✓ Development of value networks and business model frameworks that enable sustainable business transactions between the actors. ✓ Interoperable ICT enabling that these relations are easily and affordably established in practice, using as an example other more developed domains (i.e. banking, travel).
<i>HealthPGS system</i>	<ul style="list-style-type: none"> ✓ <i>Virtual Individual model</i>: A technology independent dynamic logical model comprising the personal characteristics of an individual, i.e. risk factors, identified unhealthy behaviours, personal profile, preferences, values etc. that can be used for participatory health services development. ✓ <i>HealthGuides</i> providing dynamic and tailored support including <ul style="list-style-type: none"> ○ Maintaining and updating a dynamic model of the user (VI model) ○ Monitoring the lifestyle (health behaviours) of the user ○ Identifying risks and providing personalized reactions to them based on health and prevention guidelines and updated medical evidence ○ Managing interactions between co-producers and HealthGuides ○ Behaviour change support based on e.g. persuasive technologies ✓ <i>PGS-Mall</i> <ul style="list-style-type: none"> ○ Creation of the initial VI model of the user ○ Selection of HealthGuides that match the user's VI model and intervention goals, e.g. based on user adaptive systems ○ Creating a B2B and B2C environment enabling to include local players into the game ✓ <i>PGS platform</i> <ul style="list-style-type: none"> ○ Overall architecture (reference model / reference architecture), as a distributed, open and flexible structure that assists the development of the ecosystem. ✓ New and advanced <i>sensors</i> to acquire data on health behaviours (diet / eating, physical exercise, stress, sleep, ...), environment & context and social & community behaviour, working in a coordinated way depicting a systemic image of the individual, and being more usable, comfortable and natural for the users (i.e. embedded in daily life settings). ✓ More natural, affective and adaptive <i>interfaces and actuators</i> that create a personalized multimodal and multimedia interaction to the users. ✓ <i>Semantic interoperability</i> across the continuum, especially supporting <ul style="list-style-type: none"> ○ Different health behaviours (diet / eating, physical exercise, stress, sleep, ...) ○ Co-producer data ○ Personal values in uncontrolled environments (time series with contextual data), complex data fusion and knowledge discovery. ○ Inputs to standards development: Controlled vocabularies for describing health behaviours and the virtual individual model; extensions to PHR standards ○ Coordination between sensors, services, health guides and platforms.

	<ul style="list-style-type: none">✓ Security and privacy in the Health Outreach ecosystem<ul style="list-style-type: none">○ How Individuals retain control over and use of their personal information in the ecosystem using e.g. privacy-enhancing technologies.
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The thing to remember is that all three tasks will be needed to get the job done. Given the challenges it would be advisable to approach these tasks iteratively with a learn-as-you-go approach remembering that ICT alone cannot get the job done. Projects and initiatives in this domain will need to address appropriately the full complexity from the rules of the game, to potential needs in healthcare provider re-skilling and reengineering down to the ICT realization.

CONCLUSIONS

The potential impact of the research agenda is huge. As stated in the beginning chronic conditions and diseases consume today a vast percentage of health budgets. The Health Outreach ecosystem would largely operate outside the current healthcare domain and thereby would not compete of its already limited resources. Naturally, there are several challenges in creating a sustainable ecosystem for disease prevention. The biggest one is related to the long payback time. A long term commitment and investment is needed to develop and nurture it. As stated above the results (i.e. a decrease in prevalence of chronic conditions) takes a long time to emerge. A further challenge is to reach those individuals who are at risk of developing chronic conditions as it is well known that chronic conditions are correlated with low socioeconomic status and poor education. The final challenge is that it is the users who decide if they use *HealthGuides*. In other words, the *HealthGuides* must be designed for the users (consumers).

The PREVE study shows that the job to be done is to “engineer awareness” and “instil motivation” not by telling users what to do, but by providing contextualized education, information and guidance through appropriate channels at opportune moments hoping that users will be able to internalize these and become aware and have the motivation and resources to change their lifestyle and to continue on the course.