



Feelgood – Ecosystem of PHR based products and services

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Summary 27 partners including VTT participated into the formulation of a roadmap for an ecosystem of Personal Health Record (PHR) based services. The group comprised of application and content developers, IT service providers, healthcare organizations, insurance agencies and governmental and national organizations that set policies and operating conditions. The aim with this exercise was to provide an environment for Finnish companies to excel in the international competition for PHR based services. The report starts with an analysis of the state of the art of PHR in Finland and internationally and positions PHR against national and international eHealth development activities, especially against the Electronic Medical Record. During this process it has become clear that what we are really aiming at is to contribute towards the creation of a health service environment where citizens have the possibility and means to take charge of managing their own health and acute and chronic illnesses in partnership with healthcare professionals. In this environment citizens are genuinely active and equal partners in managing their own health. In this equal partnership it is understood and accepted that whereas healthcare professionals are experts in healthcare related issues citizens are experts in how they lead their lives, what life styles they adopt and what choices they make. The new service environment would comprise of services for the public sector and of services provided in the marketplace. The PHR ecosystem partners produce solutions to both sectors. The remaining part of the report is devoted to describing and discussing the ecosystem and its components from various viewpoints. The report concludes with an outline of a plan for setting up the ecosystem. The implementation of the plan is currently ongoing in the 2 nd phase of the FeelGood project.		
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Foreword

Studies show that despite the top-level expertise available in Finland, the level at which eServices are utilized has continued to deteriorate over the past decade. This has happened despite there being some applications that would greatly benefit the national economy within a couple of years of being implemented. The structural changes required to enable the production and use of e-services in various existing operative systems would generate notable savings by reducing operating costs and optimizing benefits. In addition, the resulting improvements in the economic footing of a company that learns to successfully harness eBusiness would generate higher profits and export earnings, which would have a stabilizing effect on the public economy and the balance of current accounts.

This report provides an extensive and realistic overview of the Personal Health Record. From the innovation ecosystem's point of view, it is the record which forms the basis of the healthcare sector's operative system. In addition to the aforementioned benefits, the Personal Health Record system would have a third benefit, the positive effect on the improvement of the public health. This is quite likely the most important of the three benefits. Healthier citizens are a major boon to any nation, for economic as well as other reasons.

Efforts to bring about the three benefits just mentioned should start from e-services applications relating to the reorganization of public healthcare services aimed at promoting citizens' personal opportunities and preparedness. The publication was prepared by a team that consisted of eight leading Finnish experts under Professor Niilo Saranummi's supervision. Mr. Saranummi's decades of experience in the field, together with the expertise of the other authors, is reflected on every page of the current publication. I should like to thank all authors who participated in the writing of this current publication. My thanks are due also to all the 27 partners of the innovation ecosystem, and to the experts assigned to the project by them, who have in the joint meetings and elsewhere worked hard towards our collective achievement of the project's goals. The project would not have been possible without the commitment and multiple skills of these partners, who have also contributed to funding it.

The majority of the funding was, however, provided by the FinnWell Programme administered by Tekes, the Finnish Funding Agency for Technology and Innovation. Tekes can rightly refer to this project as one of their most significant achievements. In addition to Niilo Saranummi, Kari Kohtamäki, Antti Larsio, Kari Ruutu, and Kalevi Virta also participated in the planning of the project. My thanks to them all.

I am confident that this report, prepared to summarize the investigation phase, will be frequently consulted in future forums. One of the most immediate applications will include the Cabinet Committee on Economic Policy, which in the coming weeks will be discussing available means of promoting electronic service production in Finland. The project itself will continue, and the next step is to promote the implementation of the tasks identified during the investigation phase. The strengths that have marked the project thus far are still needed: networking, partnership, and the will to work towards a common goal.

Helsinki, 26th August 2009

Ilmo Parvinen

Chairperson of the project steering group
Sitra, the Finnish Innovation Fund

Foreword by the authors

The FeelGood project was created to analyze the state of the art in PHR and PHR based services in Finland and internationally and based on the analysis propose activities that will lead to the creation of an ecosystem for PHR based services. The objective ultimately is to enable Finnish industry to excel in the emerging international PHR market. A large number of industries, healthcare providers and other stakeholders joined the project (27 altogether, see list below). VTT took the responsibility to lead the project. FeelGood was funded partly by the participating organizations and from the FinnWell technology program of the Finnish Funding Agency for Technology and Innovation (Tekes).

The project is carried out in two phases. This report presents the results of the 1st phase during which the analysis was done and the roadmap was created. The work was organized around four workshops organized at one month intervals. In between the workshops VTT's team did the ground work of interviews and desk work of analysis of existing documentation. Participation into the workshops was extremely active with nearly 40 participants from the partners in each workshop.

The 2nd phase started in May 2009 with the implementation of activities that were identified in the road mapping process. FeelGood ends at the end of 2009 by which time we hope to have made substantial progress in launching the Finnish ecosystem for PHR based services.

We want to thank all the partners for their interest and inputs to the road mapping process. This has been an intense and interactive dialogue between all.

FeelGood partners

IT industry & service providers

- Avain Technologies
- Elisa
- Fujitsu
- Innofactor
- Itella Information
- Logica
- Mawell
- MediWare
- Microsoft
- Nokia
- ProWellness
- Pfizer
- Tieto
- Vivago

Content providers

- Duodecim Publishers
- Finnish Broadcasting Company

Insurance companies

- Ilmarinen
- Pohjola
- Social Insurance Institute

Corporate wellness (employers)

- Metso
- Finnish Broadcasting Company

Public healthcare providers

- Etelä-Karjala Social and Health Services District
- Helsinki Uusimaa Hospital District
- Turku City

Other public agencies (integrators)

- Social Insurance Institute
- Ministry of Social Affairs and Health
- Finnish Innovation Fund, Sitra
- National Funding Agency for Technology and Innovation, Tekes
- Technical Research Centre of Finland, VTT

Contents

Foreword	2
Foreword by the authors	3
Glossary	6
Executive summary	7
1 Empowering citizens and patients	10
1.1 Healthcare systems need to change	10
1.2 Citizens to take charge of their own health	12
1.3 Role of PHR	14
2 Objectives of the FeelGood project	16
3 State of the art in PHR based products and services	18
3.1 Situation in Finland	18
3.2 International situation	19
4 Ecosystem of PHR based products and services	22
4.1 PHR use cases	22
4.2 Ecosystem of PHR based products and services	23
4.3 PHR and eBusiness	25
5 Architecture, interfaces and data structures	27
5.1 Standards	27
5.2 Reference architecture	28
5.2.1 Need for reference architecture	28
5.2.2 PHR ecosystem reference architecture	29
5.2.3 Reference architecture from enterprise perspective	31
5.3 Content description	32
5.3.1 General	32
5.3.2 Electronic Health Record information	32
5.3.3 Non-clinical health information	33
5.4 Measurement Devices	34
5.4.1 Connection of a measurement device to current PHRs	34
5.4.2 Domain Information Model in Continua Health Alliance	38
5.5 Authentication and digital signature	39
5.5.1 General	39
5.5.2 Citizen perspective	40
5.5.3 Healthcare professional's perspective	42
5.5.4 Protecting information in the PHR ecosystem	42
5.6 Open source	43
6 Ecosystem of PHR products and services	44
6.1 Ecosystem members	44
6.2 Business models	47
6.3 Customer segmentation	48
6.4 Expected benefits of a PHR Ecosystem	48

6.5	Building the ecosystem	50
7	The context of the PHR ecosystem	53
7.1	Positioning against national eService initiatives.....	53
7.2	Positioning against international developments – Testbed Finland.....	54
8	Viewpoints and issues in the PHR ecosystem.....	56
8.1	Technical and semantic interoperability	56
8.2	Mobility.....	57
8.3	PHR services	58
8.4	User needs, lifestyle and motivation	59
8.5	Security, privacy and trust.....	62
8.6	Proof of value and procurement.....	62
9	Conclusions.....	65
	References	67

Glossary

<i>Term</i>	<i>Description</i>
<i>CCR</i>	Continuity of Care Record
<i>CDA</i>	Clinical Document Architecture
<i>Certificate</i>	An electronic document digitally signed by a certificate authority confirming the linkage between e.g. a person, organization, service or software and a cryptographic key ("public key").
<i>Ecosystem</i>	A heterogeneous combination of companies, interest groups and customers, with common interests in a particular domain.
<i>EHR</i>	Electronic Health Record
<i>EMR</i>	Electronic Medical Record
<i>HL7</i>	Health Level 7
<i>IHE</i>	Integrating the Healthcare Enterprise
<i>KANTA</i>	The centralized health information archive provided by the Social Insurance Institution of Finland. KANTA includes a set of national services ("KANTA-services") enabling archival of clinical patient information, citizen's view to the archived content and electronic prescription services.
<i>Kela</i>	Social Insurance Institute
<i>PHR</i>	Personal Health Record. A repository of personal health related information controlled and managed by the individual.
<i>PHR ecosystem</i>	A heterogeneous combination of companies, interest groups and customers, with common interests in providing PHR based services.
<i>PHR service</i>	A service based on the information contained in the PHR. In the most simple form, the PHR service provides a user interface for the citizen for storing information into the PHR and for retrieving information from the PHR. More advanced PHR services may include also versatile functionalities for data analysis, user feedback and information sharing.
<i>PKI</i>	Public Key Infrastructure.
<i>Qualified Certificate</i>	A certificate, which meets the requirements of the Finnish Act on Electronic Signatures (section 7/2).
<i>Reference architecture</i>	A generic architectural model describing an information system or network. The reference architecture typically describes a set of software components and their interfaces..
<i>RCT</i>	Randomized Controlled Trial
<i>ROI</i>	Return of Investment
<i>SAML</i>	Security Assertion Markup Language
<i>SOA</i>	Service Oriented Architecture. An architectural paradigm comprising loosely coupled services and the infrastructure enabling information exchange between the services. The Web Services architecture is an example of SOA.
<i>SOAP</i>	Simple Object Access Protocol
<i>SSO</i>	Single Sign-On
<i>TUPAS</i>	A common specification agreed by Finnish banks for authenticating users of internet-based on-line services.
<i>UDDI</i>	Universal Description, Discovery and Integration. A service directory specification for Web Services.
<i>Web Services</i>	A method for enabling machine-to-machine interaction over a network. A software component (Web Service provider) provides a standard-based service interface, which other software components (Web Service consumers) can call over the network.
<i>WS</i>	Web Services
<i>WSDL</i>	Web Service Definition Language

Executive summary

In several countries the discussion and subsequent planning for a nation-wide integrated electronic medical record started in the late 90's. In Finland, this led to a solution, where the electronic medical record of each citizen is to be collected into one centralized repository. Special legislation was passed in 2006 by the Finnish Parliament. This delegated the responsibility for the running of the national EMR service to the national Social Insurance Institute (Kela) and requires that all public and private healthcare providers send record elements to this repository. Kela together with healthcare providers is now in the process of taking the system into use. In the first phase it will consist of a nation-wide ePrescription service and the full EMR capability is expected in 2010. Similar national health information infrastructure programs are ongoing in several countries each with some national flavour.

Parallel to this mainly IT (eHealth) driven development arch a far-reaching and fundamental change is taking place in healthcare. This is based on the idea that citizens must take more responsibility in the management of their health and chronic illnesses. There are many names for this movement each with their special emphasis such as health promotion, and primary, secondary and tertiary prevention. The widely accepted conclusion though is that on one hand healthcare services should be citizen centred and provide a continuum of care and that on the other hand for citizens and patients to take responsibility of the management of their health and illnesses they need information, education and training, tools and services that support them and especially they need to be motivated to act responsibly in their new roles as managers of their own health (*responsibility* → *response ability*¹).

World-wide and national developments indicate that a new market is emerging to cater for the needs of citizens as *managers of their health and care*. For this, a data repository will be necessary to store and organize data generated by the citizen and patient in managing her own health and care. The record has been named the Personal Health Record (PHR). The PHR repository complements the Electronic Medical Record (EMR). They need to be interoperable and able to connect to and integrate with various applications that the citizens, patients and health service providers use.

PHR based services enable and support the transition of the current illness centred healthcare systems towards a service landscape where patients and citizens work in partnership with healthcare providers in health and care management (see Figure ES1). The co-producer approach will enable proactive interventions at an early stage of disease development when the

¹ Attributed to Dr. Ilias Iakovidis, ICT for Health Unit, European Commission

probability of full recovery is much higher and the required intervention resources much smaller than if the disease would have had time to continue its development.

There is a huge business potential in this new proactive health service landscape for all actors from device manufacturers, application developers, IT service providers all the way to the actual health(care) service providers. The barriers that are holding back this transition relate on one hand to the current structures in how healthcare services are organized and reimbursed and on the other in citizens having the abilities, tools and services to act in their co-producer role.

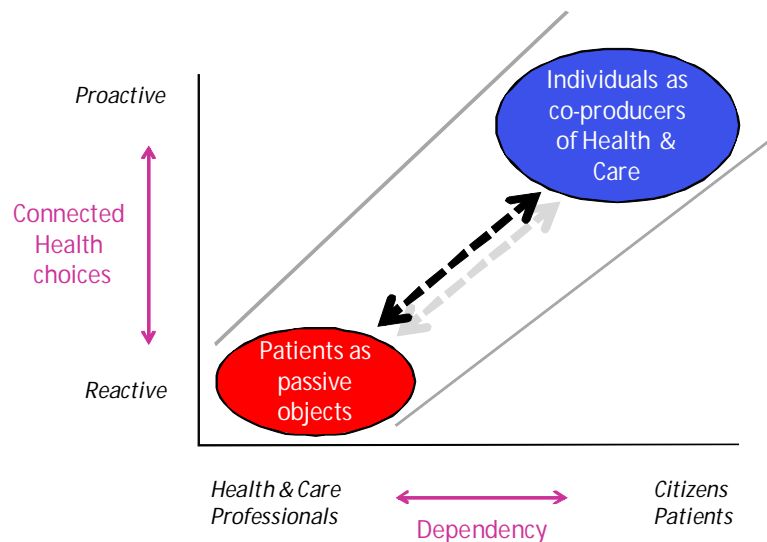


Figure ES1. The Health Continuum viewed through the co-producer approach (© David Brunnen, European Connected Health Campus).

The PHR based service ecosystem consists of two segments (see Figure 15). In the other segment, regulated healthcare services, PHR services support and enable patients to act responsibly in their co-producer role and facilitate the dialogue between the co-producers. In the other segment, market lead services, PHR services enable citizens to manage their health and wellness. Both segments make use of the PHR repository and platform services that manage access issues (security, privacy and authentication issues) and provide common services such as a service directory.

The PHR ecosystem partners and stakeholders have been identified. The question now is how the ecosystem should be launched. Quite a lot of applications are already available. There are also partners that already provide proprietary PHR repositories and platform services. There is interest in collaboration between the partners based on the reference architecture and open interfaces developed in the FeelGood exercise. What is missing is the market where the PHR ecosystem solutions could be sold. Or to put this in another way, the market today is highly fragmented. The idea of the ecosystem with a large enough volume of customers and transactions (a critical mass) is not there to be seen. Customers are buying solutions and services without a strategic view on how these can be used to improve their operations. This is largely due to the way healthcare is organized in Finland with each municipality being the responsible body for the citizens in that municipality. The potential that the PHR service ecosystem offers can only be realized when there are enough users in the system. What that translates into is a need to centralize current fragmented / distributed resources into service centres using ICT to provide the connectivity across place and time. In this highly fragmented situation some improved governance means are needed to bring the ecosystem partners together. One such possibility is the coordination that the government (Ministry of Finance) is trying to achieve through the SADe-program. That is why the FeelGood consortium made a proposal to

the SADe-program that aims to bring the parties (supply & demand) together to launch the PHR service ecosystem.

The FeelGood road mapping process has shown that there is strong interest in the PHR ecosystem. We are strong in the technologies that are needed in this (mobile, devices, open interfaces). We have been active in the international PHR scene and development circles for some time now. It has become clear that especially in the PHR domain we need to build value chains with other partners in order to reach customers and provide value. International competition is already tough and will become tougher when the markets start to develop. Economies of scale will be important, but even more important is that one can demonstrate the value of what is being offered not only in terms of health benefits but also in terms of cost savings. But getting to cost savings requires that the current healthcare incentives system is changed towards rewarding value-based health through proactive action.

Therefore although there is considerable interest towards the PHR service ecosystem it is not realistic to expect that this can be created by the actors themselves. We need strong support from the government to launch it. The government needs to be a partner in establishing the governance structures of the PHR ecosystem. We need to agree what regulations are needed to run the ecosystem and especially how the management of personal health data in a PHR repository must be handled. The incentives for healthcare providers towards value-based health need to be created. In the companies the incentive to take care of their human resources (HR) is already there. The benefits that can be accrued relate to improved productivity and decreased insurance premiums. In the public sector the biggest challenge relates to reorganizing the management of chronic diseases based on the co-producer approach. For this to happen, government involvement is needed. Finally, although a lot is already available as devices, applications and services this does not mean that the R&D phase is over and done with. What is now needed is a coordinated action plan that puts the ecosystem in place and also encourages investments in new and improved applications. Putting the ecosystem in place ideally could take place with SADe funding combined with R&D funding from Testbed Finland.

Get real – Get out of denial about the thinking it's not possible yet
Get large – Create the ecosystem and make it in sufficient scale
Get loud – Stop battling one another, join voices and work together²

1 Empowering citizens and patients

1.1 Healthcare systems need to change

National healthcare systems have been built incrementally over a long period of time. National values and culture have had a strong influence in this build-up. Consequently the systems are different, complex and rather tightly regulated. Health expenditures also vary with a large range within OECD countries. OECD and WHO comparisons show that more expenditure does not necessarily mean more or better health of the nation. Somewhat surprisingly (?) there is no world-wide consensus on how health services should be organized and reimbursed.

In the course of the past 10 – 15 years several major drivers have emerged that interactively are pushing for a systemic change in the ways that health services are organized, delivered and reimbursed. On the supply side there are three drivers. Biology based medicine (personalized medicine) has changed our understanding of diseases, their diagnostics and therapies. Second, our understanding of the role of the patient in a disease process has changed fundamentally. Whereas in the past the patient was a passive object we now understand that the patient is the centre and a co-producer of health. The third major driver is ICT, which enables the integration of data and knowledge (evidence), the virtualization of certain health services and resources, the ability to interact and engage in different ways with information and people, and the access of this anytime anywhere. On the demand side we have two interacting drivers ageing of the populations and current life styles. Combined they are leading to an increase in chronic degenerative diseases and an increase in the demand for health services, especially in disease management.

Combined these drivers point towards a future where present healthcare systems cannot be sustained. The solution to this dilemma is either to (further) restrict access to healthcare services or to *reinvent healthcare* so that better outcomes can be delivered with current resources. Ideas for reinventing healthcare have been floated now for several years. The problem though is that healthcare can be characterized as one of the “wicked problems”. It is hugely complex and changing it in one corner often leads to unexpected outcomes somewhere

² Quotation originates from Eric Dishman's (chief architect, Intel, Digital Health) presentation at the Healthcare Unbound 2008 conference where he emphasized the need for collaboration in creating a market for PHR based products and services.

else in the system. Recently The Finnish Independence Fund, Sitra funded a study that looked into how Finnish healthcare could be changed³. In the seminar that presented and discussed the report professor Michael Porter summarized his view of the current state of national healthcare systems with the following sentence: “Today, 21st century medical technology is delivered with 19th century organization structures, management practices, and pricing models”.

Current systems have been created and optimized to handle acute illnesses. However, today and in the future even more so, most of the healthcare expenditure is caused by the care of chronic diseases. Chronic diseases on the other hand can often be prevented with proper actions (i.e. health promotion and primary prevention). Furthermore their progress can be slowed with proper secondary and tertiary prevention activities. The common denominator in prevention, though, is that citizens and patients are the central resource in making it happen.

In reinventing healthcare, i.e. moving it to the 21st century using Porter’s metaphor technology will be a central agent in catalyzing and enabling the transformation and in supporting the services in the reinvented service environment. This can be summarized in three action points [1]:

- Empowering citizens and patients to take charge of the management of their own health and illnesses in partnership with healthcare professionals. For this they need information, education and training, tools and services that support them in this role and especially they need to be motivated to act responsibly in their new roles of managers of their own health (*personal*).
- Utilization of personal genetic information in prevention, diagnostics and therapies so that health problems can be detected early and solutions can be personalized to the individual (*personalized*).
- Making medical knowledge (*evidence based medicine*) available ubiquitously and integrating it with personal health records and electronic medical records (*pervasive*).

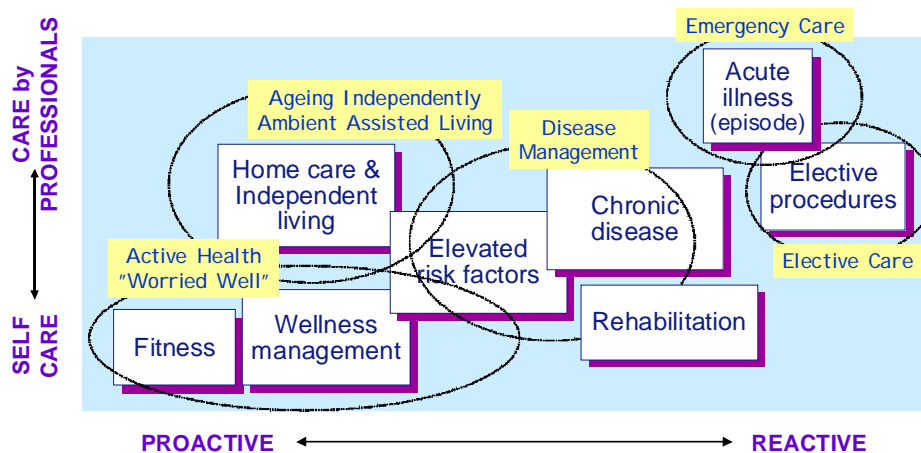


Figure 1. Health continuum where the vertical axis represents the nature of activities (proactive vs. reactive) and the vertical axis how actions are shared between citizens and healthcare professionals.

One way of illustrating the future health service landscape is the health continuum (Figure 1). It is characterized by two axes: *proactive – reactive* and *individuals (or patients) – health professionals*. At one end of the continuum are individuals who proactively manage their health and wellness and in the other end are patients who are dependent on the care provided

³ Juha Teperi, Michael E. Porter, Lauri Vuorenkoski and Jennifer F. Baron. The Finnish Health Care System: A Value-Based Perspective, 2009 (PDF: <http://www.sitra.fi>).

by health professionals e.g. during surgery or in intensive care. The emergence of the health continuum can be described as an incremental process. Initially health services were constructed to be able to react to diseases by diagnosis, therapy and rehabilitation. The increasing prevalence of chronic diseases and the understanding of the role of the patient in managing her chronic condition lead to the inclusion of the patient into the care management team. The next step was the realization that general health promotion and education alone are not sufficient means for effective primary prevention. In order to be able to act in the interests of their own health and wellness, people need access to tools and appropriate services and of course the motivation, environment, education and skills to use them for their advantage (empowerment).

Although the health continuum is conceptually easy to understand its implementation has proven to be quite difficult. On a practical level it calls for a re-division of resources, power relations and funding within the existing healthcare systems as well as for the introduction of new competencies, skills and services. All this should take place in the larger context of health policies that focus on health expenditure, quality and equity. As an example, no wonder that a recent study of the innovation capacity of the National Health Service in England was titled “All Change Please” [2].

1.2 Citizens to take charge of their own health

The fact that chronic diseases can be prevented or at least their onset can be delayed by proper actions has been known for a long time. Prevention strategies fall into three tiers:

- At the society level primary prevention is handled with public health measures and health promotion. The current thinking as presented by WHO is that they comprise two complementary actions: Public health measures that focus on creating supportive environments for health and health promotion, which focuses on supporting healthy lifestyles.
- The second tier is the healthcare system where especially GP’s, occupational health and other primary care professionals are in a key position to influence and induce lifestyle changes. Health checkups and other similar occasions provide the trigger events to discuss the need for primary prevention activities at an individual level in light of individual risk factors, family history and other indicators.
- The third and the most important tier in primary prevention is the individual herself and her immediate family.

It is generally agreed that the best strategy for prevention is to lead a healthy lifestyle. According to WHO, 77% of the disease burden in Europe are accounted for by disorders related to lifestyle. Furthermore, 70% of stroke and colon cancer, 80% of coronary heart disease, and 90% of type II diabetes could be prevented by maintaining healthy lifestyle [3].

There is little that one can do about the genes that one inherits (at least for the time being). However, our behaviour, life style, exposure to the environment and social contacts determine how our genes are expressed. Therefore identification of genes and biomarkers that cause diseases combined with an understanding how gene expression works may be a useful way to influence individuals to change their lifestyle.

However, although we are constantly “bombarded” with health promotion information that we should exercise regularly, eat healthy, control our weight, sleep enough, manage stress, not smoke and use alcohol only moderately etc. as a population we are not doing a good job in acting according to this sound advice. As an example the trends in BMI (Body Mass Index) in all OECD countries show an alarming growth rate. Based on this it should be clear that we

as individuals need assistance in primary prevention. *The question is what kind of assistance and how the assistance should be made available / offered and how to ensure that the assistance provides effective help to the individual in improving her lifestyle.*

The WHO definition [4] for disease prevention “covers measures that not only prevent the occurrence of disease, such as risk factor reduction, but also arrest its progress and reduce its consequences once established”. The definition proceeds to divide prevention into three stages: primary, secondary and tertiary. Primary prevention is directed towards preventing the initial occurrence of a disorder, whereas secondary and tertiary prevention seek to arrest or retard existing disease and its effects.

A recent OECD report [5] on disease prevention emphasizes the need to understand how (chronic) diseases are generated, i.e. how individual determinants of those diseases as well as interactions among them, over the life course of individuals cause the emergence of a disease. This includes “interpreting individual lifestyles as the result of choices regarding the consumption of commodities such as, for instance, tobacco, alcohol, and food, but also physical activity or leisure time, in the light of opportunity costs and other incentives. Health determinants that influence lifestyles are in turn the result of similar choices and incentives.” Figure 2 (left) illustrates the role of different health determinants. Of these the largest determinant is behaviour. Figure 2 (right side) illustrates the role of different activities in health management. Whereas in the past the healthcare system came to play when a health problem was diagnosed in the future its activities should extend the whole health continuum.

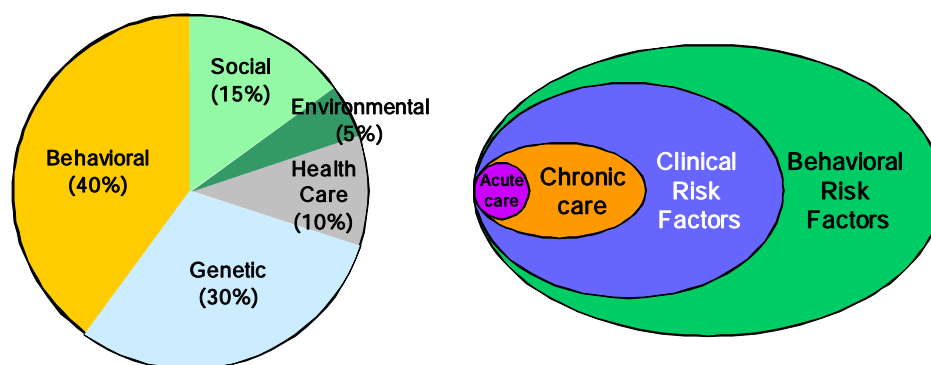


Figure 2. Left: Health determinants, Right; Health continuum from behaviour to acute care.

What are the diseases whose onset can be prevented or delayed with the right actions at the right time? Disease statistics (disease burden books) are available from many sources like WHO, OECD and CDC to name a few. The most prevalent chronic diseases with high potential for prevention include heart diseases, certain cancers, diabetes type II, stroke, COPD and some liver diseases. Other chronic diseases which may be less prevalent but have significant life impact, such as HIV/AIDS and sexually-transmitted diseases, also require a primary prevention approach. Asthma on the other hand is one example of a chronic disease that cannot be prevented but needs to be managed. Consumption of alcohol, tobacco and other harmful substances are examples of lifestyles that may lead to diseases.

Lately with increasing life expectancy the health of the brain has gained more attention, especially the prevention of dementia and Alzheimer’s disease. Mental health problems, especially depression, are an area of increasing concern especially in the working age population.

Conditions affecting mobility and activities of daily living include musculo-skeletal problems, especially low back pain, and diseases such as osteoporosis and osteoarthritis which are often co-morbid with other diseases in older populations.

Overall, in Europe today, it is estimated that over 70 % of health expenditure is directly and indirectly related to chronic and long-term conditions.

The case for health promotion and disease prevention investment is well documented. Effective – broadly available, yet personally – tailored prevention interventions need to be developed and validated. Over time, these types of interventions will make a crucial contribution to decreasing the need for costly management of long-term health conditions.

1.3 Role of PHR

Developments in ICT, Internet, Web2.0, social media etc. are leading towards a wide spectrum of virtual services (applications) that in the health sector are known as *eHealth* services. Its origins are in hospital and departmental information systems and in connectivity of the applications used in one hospital. Gradually the viewpoint widened from this hospital centred focus to an extramural setting of interconnected care providers and inclusion of citizens and patients into the care loop. The change started with telemedicine applications in the early / mid 90's. Around the turn of the millennium the hot spot were the health *.com*'s. Mobile technologies were the next wave that made services accessible anywhere. With the expansion of applications in new sub-domains interoperability has become an urgent issue. It is being addressed by international standards development organizations (SDO) such as Health Level Seven (HL7), DICOM, International Health Terminology SDO (IHTSDO), ISO TC 215 and CEN TC251. Lately these have been complemented by two organizations that write guidelines on how standards can be used for creating interoperability across applications (Integrating the Healthcare Enterprise, IHE⁴ and Continua Health Alliance⁵). The adoption and diffusion of eHealth applications is also addressed by policy level recommendations nationally and internationally⁶.

As part of these developments it has become clear that the traditional *Electronic Medical Record (EMR)*, which is maintained and updated by healthcare providers, needs to be complemented with another record that stores data generated by the patients and citizens in the course of managing their own health and illnesses. This latter has been named as the *Personal Health Record (PHR)* and defined by HIMSS⁷ as:

- *PHR is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. (The PHR is separate from and does not replace the legal record of any provider).*

PHR and EMR are separate and complementary concepts. EMR stores data from individual care episodes. Care providers are usually required through legislation and other regulations to maintain and update it on behalf of the patients. PHR on the other hand stores data that the individual generates. The individual is in full control of that record. As already stated, both records are needed in the emerging health service environment that implements the health continuum principles as demonstrated by Figure 3. They also need to be interoperable in cases where the citizen (patient) is part of the care loop as in the management of chronic diseases.

⁴ Integrating the Healthcare Enterprise, IHE: www.ihe.net

⁵ Continua Health Alliance: www.continuaalliance.org

⁶ eHealth Action Plan: http://ec.europa.eu/information_society/activities/health/policy/index_en.htm

⁷ Health Information Management and Systems Society, HIMSS: www.himss.org

Interoperability issues are addressed by the two organizations mentioned previously, IHE and Continua. IHE's focus is in interoperability of illness related data, whereas Continua focuses on interoperability in extramural settings. It's to be emphasized that security and privacy issues need proper attention in both worlds as the records store sensitive personal information.

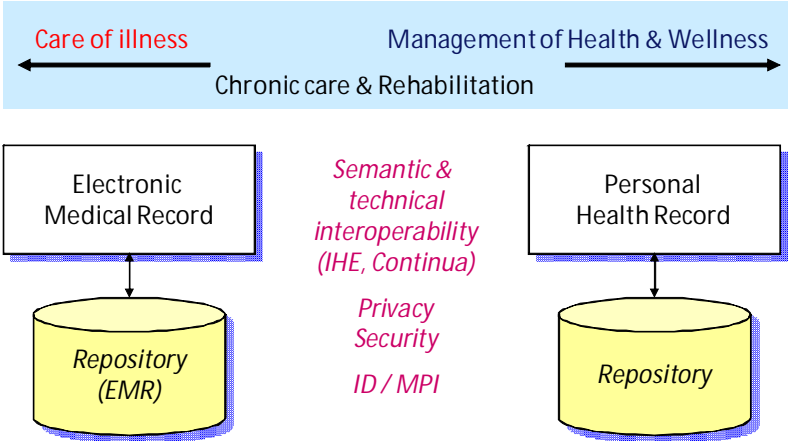


Figure 3. PHR and EMR complement each other and are both needed in the health continuum based service environment. (ID = Person's identification, MPI = Master Patient Index).

2 Objectives of the FeelGood project

The implementation of the health continuum concept of Figure 1 would mean a re-division of responsibilities between citizens (patients) and healthcare professionals. In the following we outline briefly a scenario on how this could be implemented: The primary objective for an individual is to stay healthy. In other words he is responsible of managing his health and to take on that responsibility he needs tools, services, education etc. Acute illnesses should be diagnosed as early as possible and treated with effective personalized therapies. Both self administered and professionals' supported rehabilitation services should be available after the acute episode. In case a full recovery to the state of life quality preceding the episode is not possible tools and services should be available that compensate for the loss of functional a/o mental capacity. In chronic diseases primary prevention by the individuals should be the first line of defence and should be complemented with regular checkups of risk factors. Similarly secondary and tertiary prevention should be the responsibility of the patients. They need to be supported in this by healthcare professionals. As people are different care must be taken that the services at each instance are suited to the needs of persons and can be adapted as situations change.

For all this to actually work ICT needs to be used extensively. One example of how the IT side could be deployed is what has been written by the US Department of Health in their health IT plan⁸:

- *Health IT becomes common and expected in health care delivery nationwide for all communities, including those caring for underserved or disadvantaged populations;*
- *Your health information is available to you and those caring for you so that you receive safe, high quality, and efficient care;*
- *You will be able to use information to better determine what choices are right for you with respect to your health and care; and*
- *You trust your health information can be used, in a secure environment, without compromising your privacy, to assess and improve the health in your community, measure and make available the quality of care being provided, and support advances in medical knowledge through research.*

The FeelGood project was started with this background in mind. In Finland we are already well on the road of creating a nation-wide EMR repository and service. We now need to complement this by bringing the PHR into the picture by creating a movement that will on one hand enable citizens to become equal partners in managing their own health and care in

⁸ How Health Information Technology Can Help Transform Health and Care: Defining Success (<http://healthit.hhs.gov>)

Finland and on the other hand enable Finnish companies in PHR based products and services to grow and excel in international competition by leveraging their relative strengths in an ecosystem.

A layered architecture as shown in Figure 4 was used to organize the PHR components. One of the questions that project was seeking to study was whether we should pursue a solution where there is only one nation-wide PHR repository in Finland or whether several interoperable PHR repositories could (should) co-exist. In this layered architecture the topmost layer comprises the users and the devices. Citizens, patients and service providers access the services through different channels according to need. The same applies for devices that citizens and patients use to measure a/o record vital signs and other health or care related data. They communicate with the PHR repository through different channels directly or through applications. In the middle are the services that the users use and subscribe. These are based on IT applications and services provided by vendors. The applications communicate with the PHR repository. At the bottom are the platform services that enable interoperability across applications and host the PHR repository. Platform services include an authentication service that interfaces with existing authentication services and an interconnection service that enables communication between the PHR and integrated EMR.

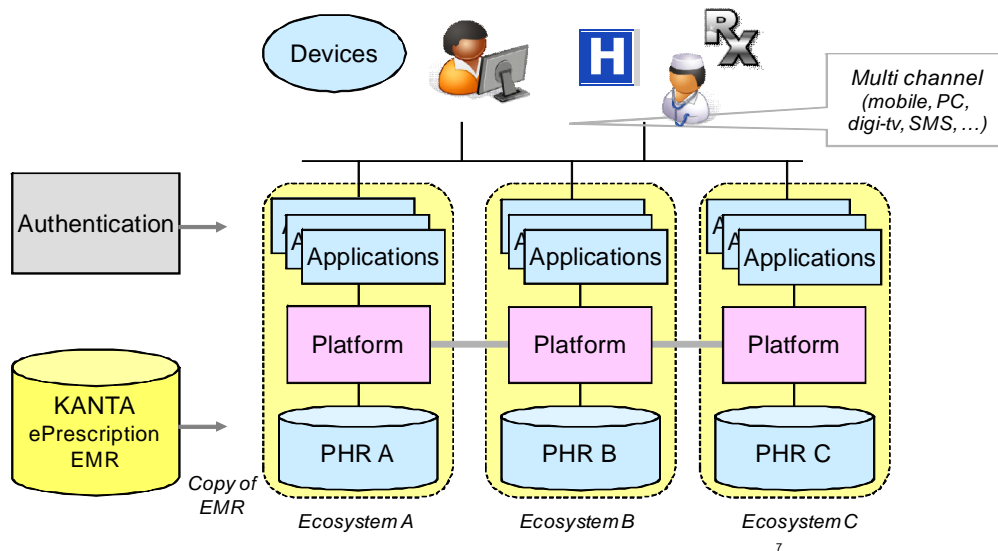


Figure 4. Architecture of PHR components.

FeelGood was organized into two phases. This report summarizes the results of the 1st phase with

1. An organized description of the elements of an ecosystem for PHR based products and services,
2. An analysis of the state of the art of PHR technologies and market development, and
3. Based on these a plan on how the ecosystem could be started in Finland.

The implementation of the plan is currently ongoing and its results will be reported separately in early 2010.

3 State of the art in PHR based products and services

3.1 Situation in Finland

As already mentioned in chapters 1 and 2 the creation of a nation-wide integrated electronic health record service is well underway in Finland. The service will be offered by the Social Insurance Institute (Kela) and all healthcare providers (public and private) are legally required to store EMR elements to this repository. The service is expected start as an ePrescription service in 2009 and first pilots of the full EMR repository are expected to start in 2010. The main body of work in this is in the modifications of the existing patient information systems to be interoperable with the repository service and then to take them into use in the existing systems.

Sitra, the Finnish Independence Fund, funded a study in 2007 that charted e-based healthcare services for citizens and patients (SAINI report)⁹. The report presented a plan and technical architecture for nation-wide e-based healthcare services. Parallel to this several municipalities and hospital districts have been developing web sites with some interactivity to extend their services to the patients. The Ministry of Social Affairs and Health has been funding a coordination project (eKat) between these¹⁰.

The National Agency for Technology and Innovation, Tekes has been running a series of consecutive technology programs in eHealth. The last in this series was FinnWell, which ends in 2009¹¹. In FinnWell one of the focus areas was technologies for personal health. Parallel to FinnWell, Sitra has been running a 5-year healthcare program, which also ends this year (2009)¹². These programs have worked in good collaboration in a number of issues. One of these is Testbed Finland. Its aim is to create favourable conditions in Finland for joint projects that seek to develop, test and evaluate new integrated service concepts in real life conditions. So far one such project, Preve, has been launched with public funding from Tekes and Sitra. At the moment Tekes has contracted the Nordic Healthcare Group to assist them in drawing up a proposal for Testbed Finland. The aim is to launch this as a joint initiative between several funding organizations. In 2008 Tekes started a new 7-year program, which focuses on innovations in the public social and healthcare system. Its focus is in innovative services and the role of technology is secondary in the program.

⁹ The report can be downloaded in PDF format from www.sitra.fi

¹⁰ <http://sp.neuvokas.foral.fi/default.aspx>

¹¹ <http://akseli.tekes.fi/opencms/opencms/OhjelmaPortaali/ohjelmat/FinnWell/fi/etusivu.html>

¹² http://www.sitra.fi/en/Programmes/health_care/health_care.htm

Finally, to speed up innovation processes in public-private partnerships six Strategic Centres for Science, Technology and Innovation have been established in Finland. One of these focuses on health and well-being. This centre was formally created in April 2009 and will start its operation in 2010. The main goal with the Centres is to thoroughly renew industry clusters and to create radical innovations. The Centres develop and apply new methods for cooperation, co-creation and interaction. International cooperation also plays a key role in the operation of the Strategic Centres. Testing and piloting environments and ecosystems constitute an essential part of the Strategic Centres' operations. In Strategic Centres, companies and research units work in close cooperation, carrying out research that has been jointly defined in the strategic research agenda of each Centre. The research aims to meet the needs of Finnish industry and society within a five-to-ten-year period. The Health and Well-being Centre has identified four strategic lines of activity. Two of these address issues in personal health (obesity and selfcare).

Companies involved in the PHR domain include:

- Elisa: <http://www.elisa.fi/>
- Itella: <http://www.itella.fi/>
- Kustannus Oy Duodecim: <http://www.duodecim.fi>
- Logica: <http://www.logica.fi>
- Medixine: (<http://www.medixine.com/>)
- Mawell and MawellCare: <http://www.mawell.fi>
- MediNeuvo: <http://www.medineuvo.fi>
- Nokia: Wellness Diary; <http://research.nokia.com/research/projects/WellnessDiary/>
- PolarElectro: <http://www.polar.fi>
- Preve (Pfizer): <http://www.preve.fi>
- ProWellness: <http://www.prowellness.com>
- Suunto: <http://www.suunto.fi>
- Tieto: <http://www.tieto.fi>
- Vivago: <http://www.vivago.fi>

Also several interesting projects are ongoing in the PHR domain in Finland:

- Personal health coach in chronic disease management – TERVA¹³
- Health promotion as part of occupational health services: Intervention study on the use of ICT – NUADU¹⁴
- New service concepts for wellness and stress management– P4Well¹⁵
- Selfcare services for citizens – eKat¹⁶
- MyWellbeing: Coper: A digital aid for personal wellbeing management¹⁷
- Healthy City – Forum Virium Helsinki¹⁸

3.2 International situation

Personal health and technologies & services that citizens and healthcare professionals can use in health and care management have a domain of increasing interest and investment in recent years. The EU has invested heavily in the R&D of Personal Health Systems in its Framework

¹³

www.sitra.fi/fi/Ohjelmat/terveydenhuolto/teho_hankkeet/Terveysvalmennusohjelma/Terveysvalmennusohjelma.htm

¹⁴ <http://www.nuadu.org/>

¹⁵ <http://p4well.vtt.fi/portal>

¹⁶ <http://www.oulunomahoito.fi/>

¹⁷ <http://www.it.abo.fi/cofi/omahyvinvointi/index.php?id=70>

¹⁸ www.forumvirium.fi/fi/hankkeet-ja-ohjelmat/terveydenhuolto/terveellinen-kaupunginosa.html

R&D programs. It is also supporting evaluation and implementation activities through its Competitiveness & Innovation Program (CIP)¹⁹ and has recently contracted the Institute of Prospective Technology Studies, IPTS to do a three year market study on Personal Health Systems²⁰.

On the policy setting side, the Commission has been deeply involved in the development and the implementation of the European eHealth Action Plan²¹. Additionally, the Lead Market Initiative (LMI) for Europe has been launched by the European Commission²². LMI will foster the emergence of lead markets of high economic and societal value. eHealth has been chosen to be one of the six markets of the LMI initiative due to its market potential in terms of growing demand and market growth opportunities, changing demographics and disease patterns, and healthcare capabilities. The focus is on the following challenges:

- Market fragmentation and lack of interoperability
- Lack of legal certainty
- Insufficient availability of financial support and Procurement issues

At national level e.g. the in UK (DH) has launched a Whole System Demonstrator Programme²³. These explore the possibilities opened up by integrated health and social care working supported by advanced assistive technologies such as telehealth and telecare.

Industry interest in this domain has strengthened considerably in recent years. One indicator that a personal health market is about to be created was the establishment of the *Continua Health Alliance* a couple of years ago. It has grown quickly and today comprises of more than 200 vendors and user organizations. Intel²⁴ played a central role in the creation and early activities of Continua. Since then two other major ICT companies have entered the field with solutions that offer PHR services to citizens, namely Google²⁵ and Microsoft²⁶. The latter has since then been very active in building an ecosystem of developers around its HealthVault service. Microsoft has also entered into discussions on how to offer the HealthVault functionality outside US. The first case where an agreement has been reached is in Canada with Telus²⁷.

There is almost an oversupply of conferences addressing the PHR domain. On the technology and interoperability front the most important are the meetings organized by Continua, HIMSS and WoHIT (in Europe). Of interest is also the European Connected Health Campus²⁸, which organized its 1st Leadership Summit in early May 2009. The Campus is an interesting development as it has engaged a number of key actors in the field and especially as the first summit produced a Manifesto for Connected Health²⁹.

Interesting examples of industries and user organizations in the PHR domain include:

- Bosch: www.bosch.com³⁰

¹⁹ http://ec.europa.eu/information_society/activities/ict_psp/index_en.htm

²⁰ <http://is.jrc.ec.europa.eu/pages/TFS/sps.html>

²¹ eHealth Action Plan: http://ec.europa.eu/information_society/activities/health/policy/index_en.htm

²² Lead Market Initiative, LMI:

http://ec.europa.eu/information_society/activities/health/policy/lmi_ehealth/index_en.htm

²³ Whole System Demonstrator Programme:

http://www.dh.gov.uk/en/Healthcare/Longtermconditions/wholesystemdemonstrators/DH_084252

²⁴ Intel Healthcare: http://www.intel.com/healthcare/index.htm?iid=health+lh_n_home

²⁵ GoogleHealth: <http://www.google.com/intl/fi/health/about/index.html>

²⁶ Microsoft HealthVault: <http://www.healthvault.com/>

²⁷ http://about.telus.com/cgi-bin/media_news_viewer.cgi?news_id=1097&mode=2

²⁸ www.echcampus.com

²⁹ <http://www.echcampus.com/collaborations/echcampus-manifesto.html>

³⁰ Bosch: <http://www.reuters.com/article/pressRelease/idUS216310+29-Apr-2009+MW20090429>.

- Dossia: <http://www.dossia.org/consumers>
- GoogleHealth: <http://www.google.com/intl/fi/health/about/index.html>
- ICW Lifesensor: <https://www.lifesensor.com/en/us/>
- Intel: <http://www.intel.com/healthcare/index.htm?iid=health+lh+home>
- Mayo Health Manager: <https://healthmanager.mayoclinic.com/Default.aspx>
- Microsoft HealthVault: <http://www.healthvault.com/>
- My HealthVet: <https://www.myhealth.va.gov/>
- Centre for Connected Health: <http://www.connected-health.org>
- Philips Directlife: <http://www.directlife.philips.com/>

4 Ecosystem of PHR based products and services

4.1 PHR use cases

As stated earlier in this report (see e.g. Figure 3) the PHR and EMR complement each other and are both needed in the transition to the health continuum service environment where citizens and patients can and are able to take responsibility of the management of their own health and care in collaboration with healthcare professionals. The health continuum comprises of four basic use cases³¹ each utilizing the PHR a/o EMR as data repository:

- **No illness, no risk factors:** Citizens manage their own health and wellness. For this they use tools and services (diet, sleep, weight, stress, fitness etc.) according to their own needs and store relevant data into their PHR's.
- **Elevated risk factors:** A (regular) health check up reveals that some clinical risk factors are elevated. This gives an impulse to the citizen to modify his lifestyle. He makes use of tools and services to support the lifestyle change and to monitor how the change is progressing. He stores relevant (process) data to his PHR. He also shares the PHR with his care provider. At the healthcare side entries will be made to his EMR from health checkups and visits. The citizens bears the main responsibility of making the lifestyle change.
- **Chronic disease:** A chronic disease has been diagnosed. This gives an impulse to the citizen to modify his lifestyle and to follow the care instructions given by the healthcare professionals. He makes use of tools and services to support the lifestyle change and to monitor how care is progressing. He stores relevant (process) data to his PHR. He also shares the PHR with his care provider. At the healthcare side entries will be made to his EMR from health checkups, visits and care episodes. The patient collaborates closely with healthcare professionals in managing his care and bears the main responsibility of managing his care.
- **Selfcare of other illnesses:** The citizen can take an active part in the management of his acute care episodes and elective procedures through the tools and services that are available on top of the PHR repository. This could comprise of (pre-)filling of forms prior to procedures in hospitals and especially self care and rehabilitation activities after hospital discharge in cases such as acute myocardial infarcts and hip replacement surgery. He stores relevant (process) data to his PHR. He also shares the PHR with his care provider. At the healthcare side entries will be made to his EMR. The patient col-

³¹ Independent living / ambient assisted living forms a fifth use case. It is not included into the use case list because it comprises on one hand of the use cases presented here that deal with the management of their own health and care in collaboration with healthcare professionals and on the other hand of the tools and services that enable the citizen to manage his daily activities and maintain social integration.

laborates closely with healthcare professionals in his self care and bears the main responsibility of managing his care.

Some examples of the possible services for the use case are listed in Table 1. However, one must emphasize that in real life, especially in case of elderly people, these basic use cases can co-exist, even all four simultaneously. Independently of the complexity of the case the challenge will always be how a citizen can gain and maintain control in managing his health and care. Part of the responsibility in this rests with industry and service providers developing tools and services for citizens. They must base their solutions to a thorough understanding of how people can be supported (and motivated) in their health and care manager role.

Table 1. Examples of PHR based services.

Social media – Web 2.0	<ul style="list-style-type: none"> • Health data Facebook • Peer groups
Health information	<ul style="list-style-type: none"> • Trusted health data sources (e.g. Terveysportti)
Your own EMR	<ul style="list-style-type: none"> • Copy of discharge summaries • Medications, inoculations, allergies, diagnosed conditions
Health and wellness	<ul style="list-style-type: none"> • Test your Health / Your risk profile (Elämä Pelissä) • Weight / diet management • Fitness, Personal (virtual) trainer • Games (e.g. balance exercises with Wii)
Disease management	<ul style="list-style-type: none"> • Health and lifestyle coaching • Remote patient monitoring • Self care
Rehabilitation	<ul style="list-style-type: none"> • Care Assessment Platform(-s) • Remote patient monitoring
eServices	<ul style="list-style-type: none"> • Contact centres / triage • Appointment booking • Prefilling of forms • Reminders • Laboratory results • Prescriptions, medication management

4.2 Ecosystem of PHR based products and services

The term "ecosystem" was coined in 1930 by Roy Clapham to denote the combined physical and biological components of an environment. In the PHR context this comprises the actors involved in the research, development, marketing and use of PHR products and services, the stakeholders who have an interest in this domain, the policy makers that set and regulate the operating conditions of the domain including interest groups and media. The ecosystem is by nature heterogeneous. Its members may have common interests, competing interests and vested interests and therefore their reasons for participating into it vary. Ecosystems form open and dynamic networks. Anyone who has an interest and is willing to follow the set rules can join. Ecosystems are constantly changing. Therefore it is impossible to draw exact contours around an ecosystem.

Figure 5 presents the main actors and stakeholders in the PHR ecosystem. The central players are the users, especially citizens, and those who make services available to users.

The citizen sees the ecosystem as a bundle of services that he can use to manage his health and care. The PHR repository integrates data created by different applications and provides value to the citizen by resending him with an organized, integrated, case-specific and personalized view into his health and care. The motivation to use a PHR is that the citizen has access to data that has been organized and integrated into “information”. If a citizen is to be a manager of his own health and care the first requirement is that he knows his health status.

In the PHR ecosystem one important aspect that defines the ecosystem are the technological standards and agreements that the members are willing to set up and follow. This refers mainly to agreements relating to technical and semantic interoperability and the adherence to international standards. These are discussed in detail in the following chapter which develops and presents a blueprint for an interoperable PHR architecture.

For service providers the ecosystem is a business ecosystem for conducting business. According to Moore [6] this ecosystem comprises of interacting organizations and individuals. Jointly they deliver goods and services to their customers who also are members of the ecosystem. The ecosystem also includes other actors and stakeholders and ultimately is the “same PHR ecosystem” that described above when viewed from the business interest viewpoint.

Ecosystem members develop their skills and competencies and that leads to developments and changes in the ecosystem. Normally ecosystems organize themselves around a lead enterprise. They define a vision that the members share and strive towards [7]. The vision can be a common business goal or be based on technologies / standards that the lead enterprise advocates.

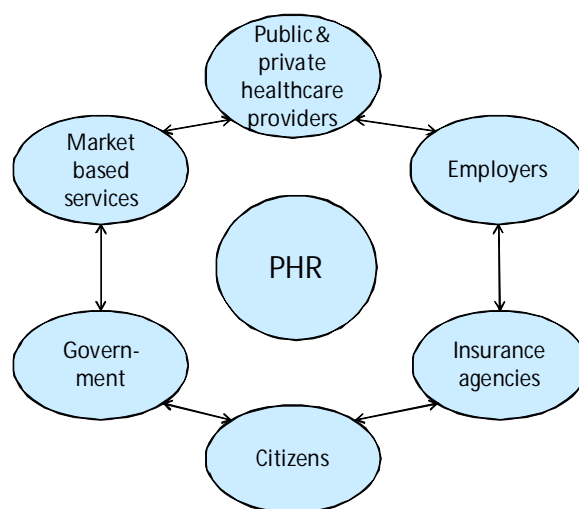


Figure 5. Main actors of the PHR ecosystem.

Business ecosystems can be compared with strategic alliances and business networks. The common theme across them is the pursuit for competitive advantages through collaboration and mutual synergies (simplifying $1+1 > 2$). Business ecosystems differ from the other collaboration models in the following characteristics [8]:

- “A standard, norm or knowhow is used by several companies. This will allow them to develop one or more central competencies
- Companies using these competencies form a strategic community of destiny based on the principles of co-evolution
- One or more companies will play the role of leader
- The leader company will have to develop a shared vision for the other members of the business ecosystem

- Founded on the basis of critical, built-in contributions, the leader's power will make it possible to orient evolution in certain competencies. It can be imagined that it is the importance of these contributions that will make it possible to build up the importance of the leader and in extension, his power.
- The position of the leader is evolutive and its behaviour primordial in the evolution of the business ecosystem.
- The key players that make up the ecosystem are heterogeneous (companies, institutions, unions, pressure groups etc.)
- The key players in the business ecosystem come from different industries and tend to have a specific activity. There is thus a convergence of industries.
- There is not necessarily exclusive membership of a single business ecosystem.
- Business ecosystems are driven by significant competitive dynamics at the intra-ecosystem level (in order to obtain the leader's position).
- The competitive logic that exists at the inter-ecosystem level (competition between several business ecosystems).
- A business ecosystem associates cooperation and competition, and thus corresponds to the logic of cooperation."

Business ecosystems can thus be seen as a set of relationships (vertical, horizontal and transversal; direct or indirect; formalized or not) between heterogeneous key players guided by the promotion of a common resource (standards, knowhow etc.) and an ideology that leads to the development of shared competencies (ecosystem competencies) [8].

From the business viewpoint the ecosystem can be viewed as the network where money flows take place. The network is based on implicit and explicit agreements and contracts between service providers, users and payers. In the PHR ecosystem one needs to notice that the users and the payers are often different entities. This adds complexity to the business models as the value has to be created and shared between many actors.

4.3 PHR and eBusiness

A dynamic and developing market creates its own challenges to the development of electronic health services. Technology solutions develop rapidly and new technology innovations appear almost daily. It is also worth noting, that in healthcare as well as, for example, in fitness portable measurement devices and systems have been in use already for several years. Today, eBusiness is part of everyday living for young as well as for elderly people. During the past decades, ICT has affected to the formation of a new era business models and business processes. Wireless and mobile technology is here to stay and is already being applied in several business industries. Several people, especially the young and middle aged have adopted the new possibilities introduced by Web 2.0 to communicate through various social networks and virtual communities. Strategic partner networks and lately business ecosystems are growing in importance both to innovate new products, services and value networks and to compete in the market place.

Geographic boundaries are losing their importance due to the increasing mobility of goods and services around the world. Therefore, traditional forms of business face severe challenges and have been forced to adapt to the new environment. At the same time, new business models are been developed to exploit new electronic solutions enabled by ICT and the Internet, which provide almost limitless availability of consumers. The Internet enables a cost-effective distribution and communication channel, even though production of information is still expensive, its reproduction and distribution is very cost-effective.

A competitive business model is novel, effective and widely distributable. There has been a long debate about how to get the consumers to pay for electronic services. This requires not only a good business idea but also changes in the operational environment and attractive enough business model to deliver the service to the consumers. Figure 6 describes the main value drivers in eBusiness. One of the most important features of a service concept is its ability to adapt to varying customer needs. The use of the service cannot also be tied to a specific time or location.

The earnings logic related to eService business models especially in a PHR context are still under development. Investigating the customers' willingness and ability to pay plays a crucial role when developing new services for different customer segments. For example with the chronically ill and the ageing population there is a clear interest for the public sector to provide and finance the use of some services. Then again, with the healthy population the consumer's willingness to pay will vary according to the consumer's personal interest. An active consumer concerned of one's own health may be willing to pay for health prevention orientated services, while a passive consumer will choose to spend his or her time and money in a different way. Employers may also be interested in providing PHR's and PHR related services to employees. This can happen in cooperation with insurance companies, which can choose to lower insurance fees as a consequence of providing services insurance companies believe will lower the risk of health problem related expenditure occurring in later periods.

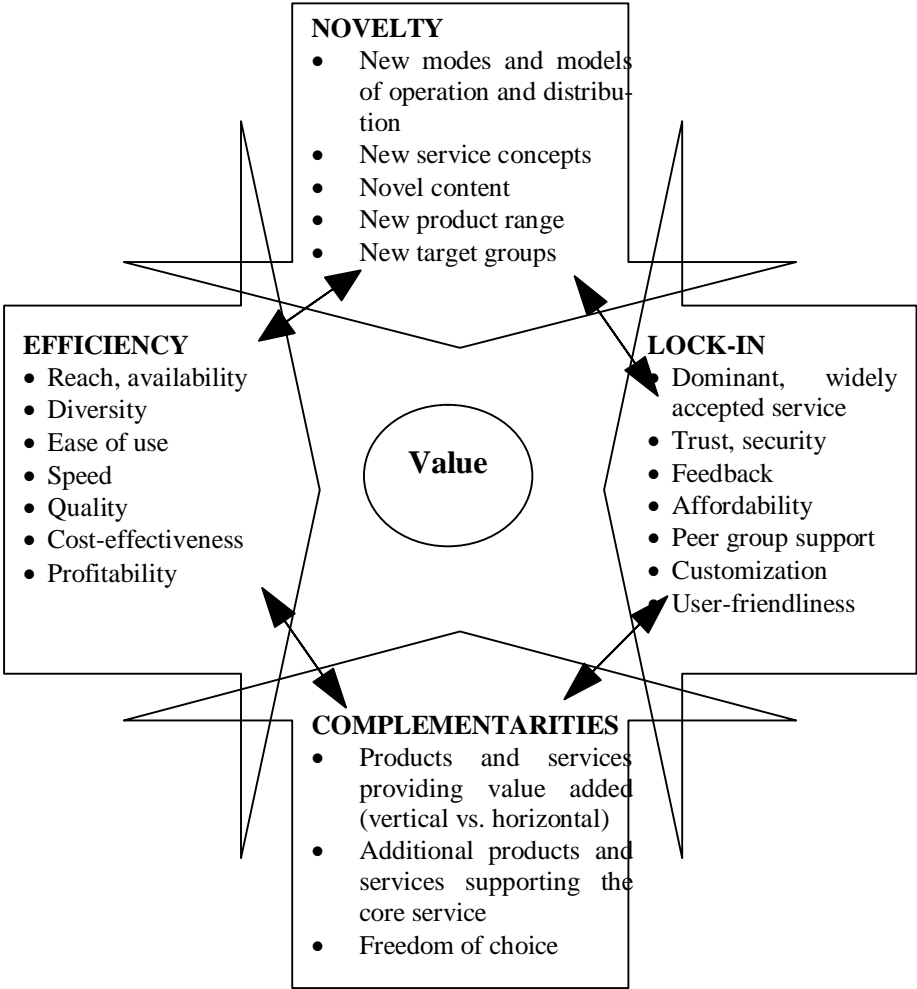


Figure 6. The main value drivers in eBusiness (adapted from [22]).

5 Architecture, interfaces and data structures

5.1 Standards

A viable PHR ecosystem calls for usage of standards at various levels. Some appropriate PHR standards are listed in Table 2.

Table 2. Standards related to PHR [16].

Category	Description	Standard
Functionality	Functionality provided by the PHR	HL7 PHR-S Functional Model
Content	Which information is included and in which form?	HL7 CCD/CDA, IHE XPHR, DICOM IOD's, ASTM CCR
Coding systems	Semantic interoperability of information	SNOMED-CT, LOINC, ICD 9/10, CPT 4/5
Information exchange	Transferring information between systems	HL7 V2&V3, IHE XDS, NCPD (X12N)
User interface	Presentation and user control	XForms, IHE RFD Profile, OASIS, Open Document Format
Device connections	Retrieving information from measurement devices	IEEE PHR, Continua Health Alliance Guidelines
Storage media	Transmission of information between storage media	USB key, CD-ROM, smart card, IHE XDR
Architecture	Realisation of the service from networked components	SOAP, WSDL, WS-I

Essential standards from the ecosystem perspective are related to contents, coding systems, information exchange, architectures and connection with measurement devices. Content and coding system standards defining the semantic description of information will be considered in more detail in Chapter 5.3.

Information exchange standards enable the transfer of PHR content between information systems. They include definitions of frame structures for carrying the PHR content and enabling appropriate processing of the payload at the receiving side. The HL7 v2.x -message standards are in extensive use in clinical care applications and migration to the next version (HL7 v3) is also going on. For example, in Finland HL7 v3 messages will be used in the national KANTA-services which include a national Electronic Medical Record (EMR) archive, ePre-

scription service and a citizen's EMR view service. Additionally, the IHE³² has defined profiles, which define mechanisms for information exchange. The XDS profile is based on generic ebXML³³ definitions and supports retrieval and storage of EMR content.

The architecture-level standards provide the overall framework enabling the interaction of networked service components. Service Oriented Architectures (SOA), in particular the Web Services (WS) architecture is highly relevant from the PHR ecosystem perspective. For example, the national KANTA-services are based on the WS architecture. In SOA the service visible to the user is provided by a combination of several interacting service components. The service components can be redesigned and deployed according to the needs of the dynamically changing business environment. This way, more flexibility can be achieved compared to the legacy "monolithic" information systems. The SOA enables loose coupling of services and is therefore highly applicable to ecosystems consisting of service components from different organisations. Individual service components are typically described by using the WSDL (Web Service Definition Language) and communication between service components is based on SOAP messages.

The purpose of device connection standards is to enable retrieval of measurement data from personal wellness devices such as wrist computers and heart beat rate meters. The Continua Health Alliance^{34,35} community has been established in 2006 by a group of large international companies. One important objective of the community is to promote and support measurement device interoperability particularly focusing in chronic disease management, independent living, proactive health and wellness products. The Continua Health Alliance importantly contributes to integration of information, which enables new services for citizens. The Finnish participants in Continua are Bluegiga, Kustannus Oy Duodecim, Medixine, Nokia, Polar Elektro, Suunto and VTT. Currently, the community includes more than 200 different organizations and about 1000 individual experts contribute to the activities in various workgroups. The Continua Guidelines (v1) -specification has been published in 2008. In addition to the device interface it includes an interface definition for transferring measurement data into the EMR and PHR. Device connection standards will be described in more detail in Chapter 5.4.

5.2 Reference architecture

5.2.1 Need for reference architecture

An architectural approach for providing PHR services has been earlier proposed in the SAINI-report [15]. The SAINI report builds on the assumption where the PHR services are provided by a single national solution. This approach does not cover the needs of a PHR ecosystem, which would include several interoperable PHR's and related wellness services. The Center for Information Technology Leadership (CITL) describes reference architecture for interoperable PHR's and has estimated the benefits achieved by the interoperable PHR architecture to be considerably higher compared to the benefits of other architectural models³⁶. Both the SAINI and CITL-architectures do not cover connection to measurement devices, which is a central element in the reference architecture of Continua Health Alliance (Guidelines 1.0: "reference topology").

³² <http://www.ihe.net/>

³³ <http://www.ebxml.org/>

³⁴ <http://www.continuaalliance.org>

³⁵ <http://www.teknologiateollisuus.fi/file/4675/Continua-raportti-julkinen2.pdf.html>

³⁶ http://www.citl.org/pdf/CITL_PHR_Report.pdf

The FeelGood -project considers important to complement the existing architectural approaches by defining an ecosystem level architectural description covering the service components and related interfaces contributing to PHR services. The reference architecture does not intend to specify a certain implementation of a PHR service or a PHR ecosystem. Rather, it provides a framework which supports comparison and observation of different service provision approaches and their interoperability issues. Moreover, the reference architecture is not defining detailed interfaces, but provides overall interface descriptions and refers to relevant standards which could be applied. The ecosystem level reference architecture addresses particularly the interfaces which are relevant for interactions between two organisations.

The objective of the reference architecture is to guide the service evolution so that different PHR services would be "topological subsets" of the reference architecture. In this case, the reference architecture can be referred in service descriptions in order to allow better comparability between different solutions.

5.2.2 PHR ecosystem reference architecture

Figure 7 presents a PHR ecosystem reference architecture as compiled based on the FeelGood project workshops and interviews. The architecture includes generic service components and interfaces covering a wide range of different PHR services and ecosystems. A typical PHR service or ecosystem includes only a subset of the components and interfaces shown.

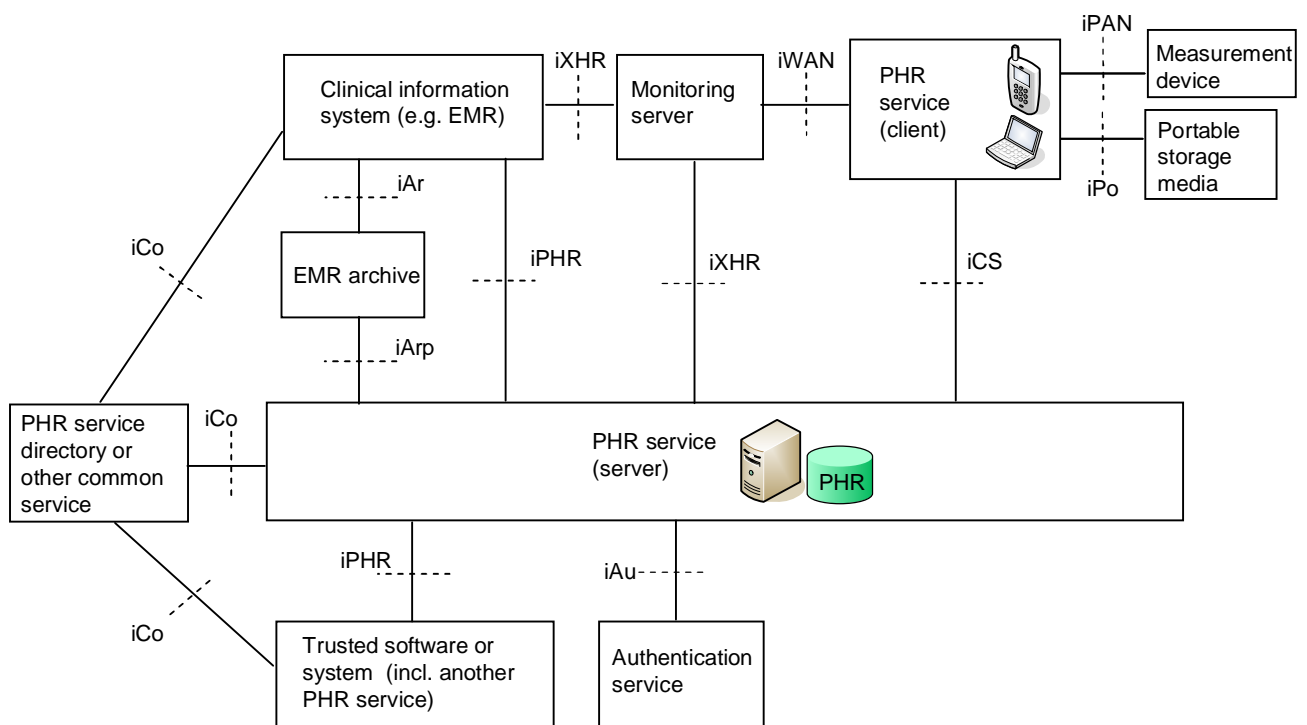


Figure 7. PHR ecosystem reference architecture.

The most central components of the reference architecture are the PHR service client and server. The client part is included in all and the server part in almost all PHR solutions. The client is either a specific software application or browser - typically running on a PC or a mobile phone. The client part can additionally be connected to measurement devices and specific monitoring servers for exchanging data. This part of the reference architecture covering the interfaces (iPAN, iWAN and iXHR) maps to the reference topology described in Continua Guidelines. The client part may also be connected to a separate storage media (iPo interface).

The server part may exchange information with other applications and services. For example, clinical applications may provide EMR data directly to the PHR service or alternatively the PHR service may retrieve information from EMR archives. Information exchange with other PHR services is also possible, which allows information to be shared between PHR services.

Table 3. PHR ecosystem reference architecture interfaces.

ID	Description	Standards (examples)	Status
iAr	Storing EMR information in centralized EMR archive and retrieval information from the archive. Used especially by organization-specific EMR applications.	WS-interface for transferring clinical EMR information as HL7 CDA R2 documents. HL7v3 used are messaging standard.	National specifications in Finland concerning the KANTA-services. Implementation on-going.
iArp	Retrieval of EMR information from the archive for PHR use. Information content limited compared to the iAr interface.	WS-interface for transferring clinical EMR information as CCD or CCR documents. HL7v3 or IHE/XDS used as messaging standard.	National specifications are so far not covering this interface. The KANTA-specifications include only a browser-based interface for information viewing (service expected to be available by 2011).
iPHR	Transfer of personal health information from one PHR service to another service or application.	WS-interface, which utilises CCD or CCR standards concerning clinical information.	Open interfaces are available in Health Vault and Google Health services (HV Class Library, Google Health Data API).
iXHR	Health monitoring measurement data transfer from the monitoring server to the EMR or PHR.	Continua Guidelines 1.0 defines the interface, which utilizes the PHMR-information structure and IHE/XDR profile.	So far, health monitoring data are usually not transferred to EMR but stored separately.
iWAN	Health monitoring data transfer from personal devices (telephone, PC, hub) to a monitoring server.	The topology defined by Continua Guidelines includes this interface although its detailed definition is not included in version 1.0 of the Guidelines.	Typically a device or manufacturer specific interface is used. Standard-based, open solutions are not available.
iPAN	Health monitoring data transfer from a measurement device to a personal device (telephone, PC, hub).	Continua Guidelines 1.0 defines the interface based on ISO/IEEE 11073 standards.	Typically a device or manufacturer specific interface is used. Availability of standard based, open solutions is limited.
iPo	Data transfer between a personal device and portable storage media (e.g. USB memory).	The IHE/XDM profile defines the principles for storing and reading information.	Typically, importing and exporting of information to/from the PHR application has not been implemented.
iCo	Usage of common PHR services. For example, updating the service description in the service directory or retrieval of information concerning other PHR services.	Web Services standards, e.g. UDDI, can be utilised.	Common PHR services and their interfaces have not been defined.
iAu	Interface for user authentication service. The interface takes care of user authentication and delivers authentication information to the PHR service.	National specifications (TUPAS) available for authentication services provided by banks. Also the SAML protocol is available for authentication data.	Bank authentication largely used in Finland. Certificate based solutions (e.g. the citizen certificate) have not been largely adopted by the citizens.
iCS	Interface between the client and service parts of the PHR service.	Typically an internal interface of the PHR service.	PHR software provider specific interfaces are largely used in commercial applications.

Other trusted services in Figure 7 may include a wide range of citizen's online services - extending beyond the healthcare domain. One example of such services is the Finnish national portal for accessing public online services, which is currently under preparation ("Asiointitili"³⁷). Furthermore, the PHR service can be connected to common services which support the formation and maintenance of the ecosystem. An example of such component is a service directory, from which applications can retrieve meta-information about the available PHR services. This meta-information typically includes service descriptions, interface specifications and availability information.

Descriptions, standard references and status information concerning the ecosystem architecture interfaces have been listed in Table 3. It can be seen that the required standards for PHR ecosystems largely exist. However, software and device manufacturers are not using them very actively. Most of the currently existing PHR services are stand-alone systems with no or limited interoperability with other services. The reference architecture and interface descriptions presented above are preliminary and will be updated in the course of the FeelGood project and its extensions.

5.2.3 Reference architecture from enterprise perspective

From the perspective of a specific organisation, a layered approach is typically used for presenting the reference architecture (Enterprise Architecture, EA)³⁸. Figure 8 provides an example of such presentation for the PHR reference architecture. The lowest layer is represented by the enterprise's information systems and basic services. The second layer contains service components which can also be located outside the enterprise. The service components are used by applications which reside on the third layer.

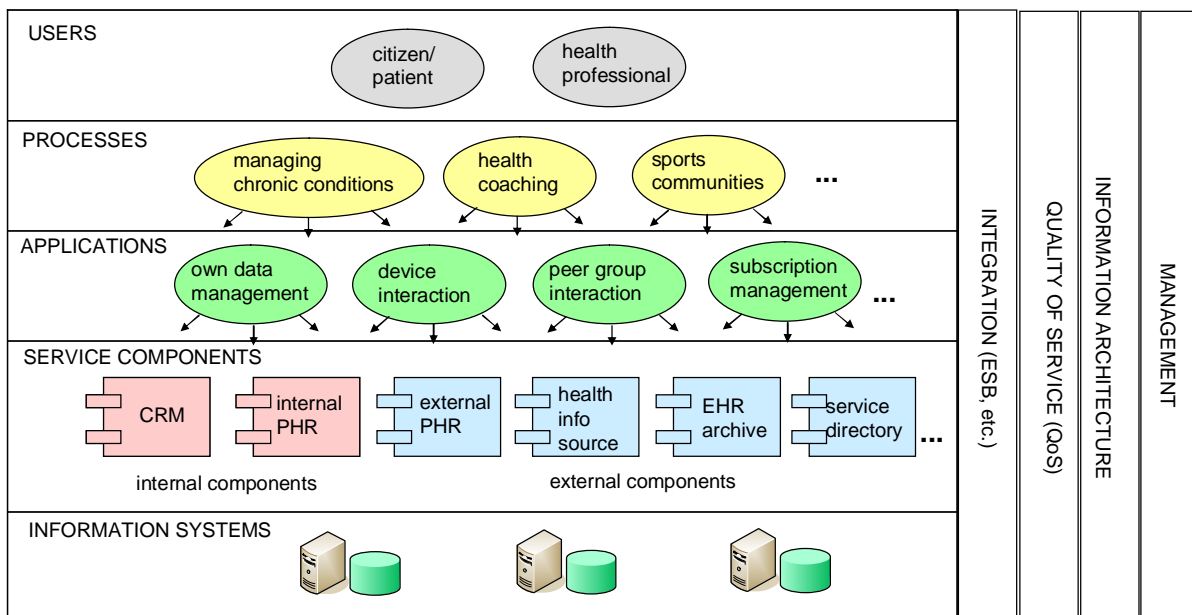


Figure 8. Enterprise reference architecture for PHR services

Applications are used by a set of processes on the fourth layer. Finally, the fifth layer contains the users which can be roughly divided into citizens and professional users. The vertical lay-

³⁷ http://www.vm.fi/vm/fi/13_hallinnon_kehittaminen/05_it_toiminta/01_valtit/01_sahkoinen_asiointi/02_asiointitili/index.jsp

³⁸ <http://www.ibm.com/developerworks/library/ar-archtemp/>

ers take care of communication between layers, quality of service, matching of information structures and management services, including security management.

In addition to the approach described above, the enterprise level reference architecture can be presented as a functional architecture describing the relevant functionalities for a PHR service. This kind of architectural model has been developed in the MyWellbeing project³⁹.

5.3 Content description

5.3.1 General

Structural and semantic definition of information contents has a central role in achieving information mobility between services. Standard document structures facilitate correct reception of information. In addition to defining the information structure the document standards include references to vocabularies needed by the receiving application to understand the meaning of the incoming information. In particular, the document standards (e.g. CDA, CCD and CCR) include a mechanism for linking the contents to clinical coding systems, such as SNOMED-CT and ICD 9/10.

International standards and coding systems have been applied and adapted in several ways for national use, and therefore interoperability of clinical systems across national borders is limited. Several current activities, e.g. the epsOS-project⁴⁰ are currently addressing the need for interoperability at European and global levels.

5.3.2 Electronic Health Record information

The HL7 CDA document standard (recently especially release R2) is largely used for describing EMR content. Transferring the patient's disease history between systems is needed for example in the case when the patients care unit is changed. For this purpose the ASTM-standardisation organisation⁴¹ has developed a content description standard (Continuity of Care Record, CCR)⁴². It describes a subset of the EMR including all information needed to continue the care of the patient at a new organisation. A similar document standard (Continuous Care Document, CCD) has been developed in co-operation between the HL7 and ASTM⁴³. This standard is a limited version of CDA defined as a set of constraints on CDA. Both structures, CCR and CCD, are well-suited for clinical information in PHR services. They cover same information contents so that conversions between the standards can be easily carried out.

CCR and CCD structures are not designed for exchanging health monitoring measurement data. For this particular purpose, HL7 and Continua Health Alliance have defined a set of CCD constraints, which guide usage of the document structure for measurement data. As a result a new specification, Personal Health Monitoring Report (PHMR)⁴⁴, has been created. The PHMR is particularly suited for transferring measurement data to the PHR.

³⁹ <http://www.it.abo.fi/cofi/omahyvinvointi/>

⁴⁰ <http://www.epsos.eu/>

⁴¹ <http://www.astm.org/>

⁴² ASTM E2369 - 05 Standard Specification for Continuity of Care Record (CCR)
<http://www.astm.org/Standards/E2369.htm>

⁴³ HL7 Implementation Guide: CDA Release 2 – Continuity of Care Document (CCD), <http://www.hl7.org/>

⁴⁴ HL7 Implementation Guide: Personal Healthcare Monitoring Report (PHMR), <http://www.hl7.org/>

5.3.3 Non-clinical health information

From the perspective of PHR services it is important to note that the document standards (CCR, CCD and PHMR) described above are oriented to disease care. They do not include information related to proactive healthcare such as diary notes and measurements on nutrition, physical activity, sleep and stress. Furthermore, they are not applicable for describing goal settings such as changes in life style.

The content description approach proposed by the Indivo -community⁴⁵ is based on a schema collection. The existing Indivo schemas are related to clinical information. However, the schema collection is basically flexible and can be complemented by custom schemas. This would allow new schemas to be developed for own diary notes and measurement data. The Indivo community also accepts new schemas to be added to the collection. So far, there is not much evidence of how largely the Indivo model will be adopted in PHR services. For example, Indivo was not included in a recent study on PHR adoption⁴⁶, which showed that 60% of PHR services support CCR and/or CCD.

Common vocabularies covering both clinical and non-clinical contents are essential in order to achieve semantic PHR interoperability. The national FinnOnto project has developed an ontology library (ONKI)⁴⁷ which offers an access to the Health Promoting Ontology (Finnish acronym: TERO). TERO consists of three parts: The European Multilingual Thesaurus on Health Promotion (HPMULTI)⁴⁸, the Finnish Stameta vocabulary and a subset of 2500 terms of the MeSH vocabulary (Medical Subject Headings). The TERO ontology covers widely the terminology related to health promotion and it is particularly suited for indexing public health information. The "Compendium of Physical Activities" [17] contains a classification, which specifically addresses physical activities. The primary objective of the compendium is to classify activities according to their typical energy consumption, but it can be applied more widely in PHR applications.

The vocabularies referred above do not cover semantics for describing personal health diary notes and measurements. For example, the term "jogging" is described in several vocabularies, but there is no linkage to related observations, such as jogging route length, duration and average heart rate during the exercise. In VTT's contribution to the international NUADU project, an ontology-based approach for linking observations and measurement devices with wellness terminology has been introduced [18].

Until now, health promotion information has typically been handled within isolated services and consequently, the lack of ontologies for linking vocabularies with health diary notes and measurement data has not been considered a problem. However, concerning the building of an ecosystem of interoperable PHR services, these limitations of vocabularies and ontologies are remarkable. Information may always be transferred between systems in free text or PDF documents without semantic meaning, but in this is case it is not possible to adapt information to the format preferred by the user in a specific use context. Therefore, the need for developing new semantic information content definitions is evident. One development objective could be a new ontology complementing the existing TERO-ontology concerning personal diary notes and measurements. The ontology services provided by the ONKI environment could be used in accessing and maintaining the new ontology.

⁴⁵ <http://indivohealth.org/>

⁴⁶ Chilmark Research, October 2008

⁴⁷ <http://www.yso.fi/>

⁴⁸ <http://www.hpmulti.net/>

5.4 Measurement Devices

One of the most distinct differences between a Patient Health Record (PHR) and an Electronic Medical Record (EMR) is the fact that EMR contains data measured by healthcare professionals (e.g., X-ray images, blood tests, etc.), while a PHR contains also data measured at home, by the patient himself. The data measured at home may be for management of a chronic disease (e.g., blood pressure, blood glucose), for management of personal wellness (e.g., heart rate and step count) or for independent living (e.g., alarms from a care phone, reminders for medication intake).

5.4.1 Connection of a measurement device to current PHRs

The currently available, international PHR's like Microsoft HealthVault⁴⁹ and ICW LifeSensor⁵⁰ support connection of measurement devices through their proprietary software applications. The manufacturers who support the HealthVault-way of connecting, can get a "Works with HealthVault" logo for their device. The idea is that the user can easily recognize, which devices are supported and can be used with the PHR he is using. Similarly, the devices supporting ICW LifeSensor type of connection can get a "Speaks LifeSensor" logo. (Figure 9). These ways of connecting a measurement device to a PHR are not compatible, however. Thus, a manufacturer, who wants his device to be compatible with several PHR's, has to write separate drivers for each PHR he wants to support. From the viewpoint of companies maintaining or using PHR's (or manufacturing devices), there is a clear need for a standardized way of connecting devices to a PHR.



Figure 9. Logos given by PHR companies for devices that are compatible with their respective PHR service (Microsoft HealthVault and ICW LifeSensor).

A device can be connected to HealthVault PHR through MS HealthVault Connection Center application (HVCC). HVCC is a free software application currently running on PCs, in Windows XP and Windows Vista operating systems. The application is run on the background (Figure 10) and it can be used to upload all measurement data from the device to HealthVault database in the Internet. In order to be able to upload data to HealthVault, the user has to have a HealthVault account. Currently, an account can be created only from addresses in the USA, so HealthVault can currently not be used from Finland.

In addition to HVCC application, a device driver is needed as well. This is normally written by the device manufacturer. The driver receives data from the device, converts the data and outputs to HVCC application. The driver application is a Windows Portable Device (WPD) – driver. Device manufacturers, who are manufacturing devices compatible with Microsoft HealthVault are: AND medical, Home Diagnostics, Homedics, Lifescan, Microlife, Nonin, Omron, Polar Electro and Tanita.

⁴⁹ www.healthvault.com

⁵⁰ www.idn.icw-global.com

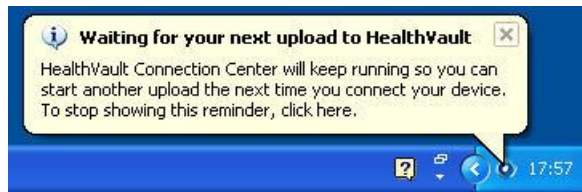


Figure 10. Health Vault Connection Center application runs on the background on a PC and sends data from a measurement device to MS HealthVault database in the Internet.

ICW LifeSensor PHR works similarly to HealthVault. In this case, a Java application called LifeSensor Device Connectivity for Consumer's Client (DCC) is installed on a PC (Figure 11). Device manufacturers, who are manufacturing measurement devices supporting ICW LifeSensor are: Aipermon, Beurer, Intel, Omron, Polar Electro, Roche and Viasys Health-Care.

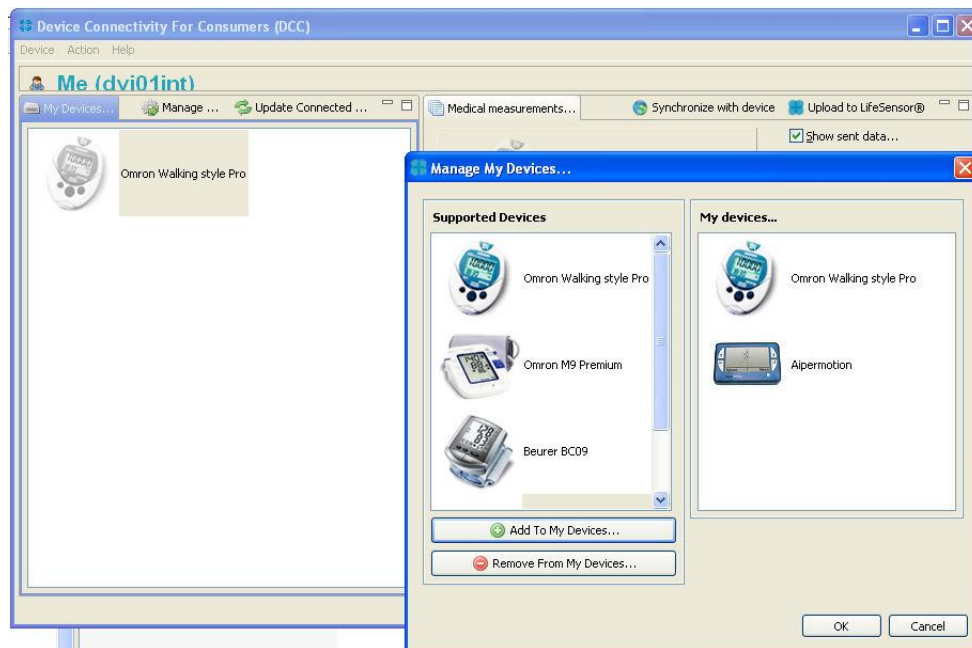


Figure 11. ICW LifeSensor Device Connectivity for Consumer's Client application for PC. It can be used for sending measurement data from a measurement device to ICW LifeSensor PHR on the Internet.

There are plenty of measurement devices suitable for home measurements available on the market and more devices are coming. Typical examples of measurement devices that a typical user can connect to a PHR are presented in Table 4. Also interface that the device currently uses in data transfer is mentioned (device interface). The semantic interface (e.g., communication protocol, data format) is usually not published by the device manufacturer, because both the device and the PC application come from one manufacturer.

Table 4. Examples of devices that a typical user could connect with a PHR. C = manufacturer is involved in Continua Health Alliance. HV = device is compatible with Microsoft HealthVault.

Category	Example Web link	device	Interface	C	HV
Blood pressure monitor	A&D Medical www.andmedical.com	UA-767	Bluetooth	c	hv
Blood pressure monitor	Omron HEM-790IT www.omron-healthcare.com		USB cable, proprietary interface	c	hv
Weight scale	Tanita HD-351BT www.tanita.com		Bluetooth	c	hv
Weight scale	A&D Medical UC-324THW www.andmedical.com		Proprietary USB transmitter-receiver (ActiLink)	c	hv
Blood glucose monitor	BodyTel GlucoTel www.bodytel.com , www.bluegiga.com		Bluetooth, cell phone, GSM	c	
Blood glucose monitor	LifeScan OneTouch UltraEasy www.lifescan.com		USB cable, proprietary interface	c	hv
Blood glucose monitor	Roche Accu-Chek www.accu-chek.fi		Proprietary wireless IR-transmitter (SmartPix)	c	
Blood glucose monitor	Home Diagnostics TRUEtrack www.homediagnosticsinc.com		USB cable, proprietary interface		hv
Blood glucose monitor (continuous measurement)	Medtronic Guardian Real-Time CGMS www.medtronic.com		CareLink USB adapter (wireless)		
Pulse oximeter	Nonin Onyx II 9560 www.nonin.com		Bluetooth Medical Device Profile (MDP)	c	hv
Heart rate monitor	Suunto t6c www.suunto.com		USB cable, proprietary interface	c	
Heart rate monitor	Polar F55 Heart Rate monitor www.polar.fi		USB FlowLink (proprietary), IR	c	hv
Step counter	A&D Medical XL-20 www.andmedical.com		Proprietary USB transmitter-receiver (ActiLink)		hv
Step counter	Omron Walking style PRO www.omron-healthcare.com		USB cable, proprietary interface		hv
Step counter	Aipermon www.aipermon.com		USB (supports ICW LifeSensor PHR)		
Step counter + GPS	Garmin Forerunner 405 www.garmin.fi		ANT + USB		
Activity monitor	BodyBugg www.bodybugg.com		Bluetooth, USB		
Activity monitor	Polar FA20 Activity Computer www.polar.fi		USB cable	c	
Activity monitor	Philips DirectLife www.newwellnessolutions.com		USB adapter	c	
Activity monitor	Philips/Respironics ActiWatch www.actiwatch.respironics.com		USB cable	c	

Heart rate monitor & cell phone with GPS and applications	Nokia N79 Active kauppa.nokia.fi/nokia-fi/product.aspx?sku=3974568	MMS, eMail, Bluetooth, USB	c
Heart rate monitor, GPS	Elisa FRWD B/W600 www.frwd.fi	Bluetooth, USB	
GPS logger	Elisa myLogger www.mylogger.fi	USB cable	
Activity and sleep monitor	Vivago Active www.vivago.fi	Proprietary wireless + USB adapter	
Independent monitoring	Vivago Care www.vivago.fi	Proprietary wireless + USB adapter	
Sleep monitor	Emfit SafeBed www.emfit.fi	Ethernet	
Medication monitor	Cypak CPK082 & MR081 reader www.cypak.se	GSM/GPRS, NFC or USB SMS, e-Mail, XML	- c
Medication monitor	Med-eMonitor www.informedix.com	Via phone line to server	
Integrator device at home	Intel Health Guide PHS6000 www.intel.com/healthcare	USB, Bt, Rj-45, Microphone, camera, speakers	c
Integrator device at home	Philips Motiva www.healthcare.philips.com	Bluetooth, ...	c
Integrator device at home	HealthBuddy www.healthhero.com	RS-232, USB, Bluetooth, Ethernet	
Data acquisition	Vivometrics LifeShirt www.vivometrics.com	Flash-card, Bluetooth	c
Mobile diary	Nokia WellnessDiary re-search.nokia.com/research/projects/WellnessDiary/	E-mail, MMS, ...	c
Heart rate: RR interval logger	Firstbeat Technologies BodyGuard www.firstbeat.fi	USB	
ECG recorder	Commwell Health-eChair & Physi-oGlove www.commwell.us	Bluetooth	

The measurement devices currently available for home measurements use very different interfaces for data transfer between the measurement device and the PHR (Figure 12). In most cases, the measurement device is connected either via a wired or wireless connection to PC, which then sends the data over Ethernet to a PHR. For wired connections, USB cable is currently the most used and in wireless connections, Bluetooth is used most. Another possibility is to transfer the data from the measurement device to a cell phone and from there over the Internet to a PHR (e.g., BodyTel GlucoTel). The third possibility is to move measurement results directly from the measuring device to a PHR, e.g., by using a GPRS- or Ethernet-connection, or a modem connection over a phone line (e.g., Cypak and Nokia WellnessDiary). The fourth possibility is to connect the device first to the patient's terminal, which is connected to Internet. Such a terminal can also give reminders or show educational material to the patient (e.g., Philips Motiva and Intel Health Guide). The fifth possibility is to transfer the measurement data wirelessly from the measuring device to a base station, which is connected to Ethernet (e.g., Vivago).

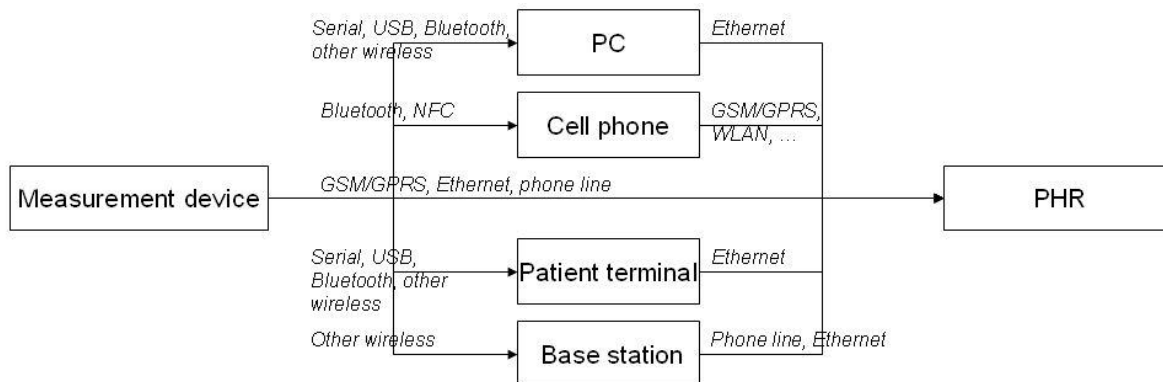


Figure 12. Different ways of connecting the measurement devices to PHR (device interface)

5.4.2 Domain Information Model in Continua Health Alliance

It does not make sense to develop yet another specification for device connectivity (such as that of MS HealthVault or ICW LifeSensor) for a PHR that is targeted mainly to the Finnish market. It would make more sense, to follow an international standard.

Such a standard is now being developed in Continua Health Alliance. The standard covers many aspects of device, PHR and service connectivity. At least GoogleHealth and Dossia have informed that they will support Continua and thus devices following Continua specifications. The first Continua compatible device was published in January 2009: Nonin PalmSat 2500 oximeter. To date, four new Continua compatible devices have been published after the first device: Nonin Onyx II 9560 Wireless Fingertip Pulse Oximeter, A&D Medical UA-767PBT-C Blood Pressure Monitor, A&D Medical UC-321PBT-C Weight Scale and Roche Accu-Chek Smart Pix Glucose Device Reader. More Continua compatible devices can be expected to be available on the market in near future. The Continua V1 specification was finalized in February 2009 and it is currently available also to non-members (since July 2009). When designing and implementing a new PHR, it currently seems most appropriate to support Continua and devices that support this standard.

Continua has named the measurement device as “agent” and the terminal that is used to control other devices as “manager. By definition, the agent (measurement device) has a limited memory capacity, processing capacity and battery power. The agent can be connected only to one manager device at a time and it is typically a low-cost consumer device. It has fixed configurations and its data type and format do not change. It uses intermittent connections and disconnects when inactive. For example, a weight scale is a typical agent device.

By definition, the manager device (terminal) has more memory and processing power and it usually gets power from wall or larger capacity battery. It can have a connection to several agents (measurement devices). E.g., a cell phone and a PC are typical examples of a manager device.

The agent and manager devices can be connected, e.g., using a USB cable or a wireless Bluetooth connection. During the first connection, the manager needs configuration information from the agent device. The agent sends its configuration data to the manager. Next, as the measured value changes, only the new value is sent. During the next connection, it is no longer necessary to transfer the configuration information, if they are still in manager memory.

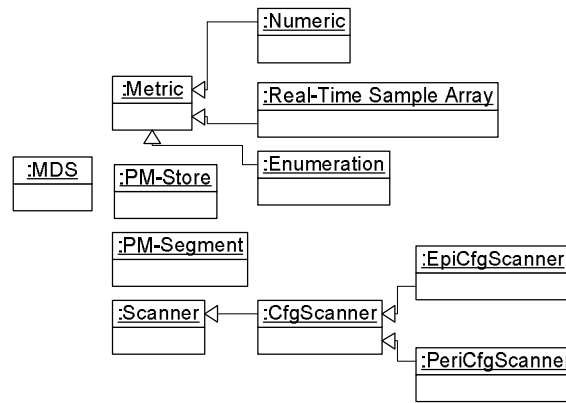


Figure 13. Domain information model (Continua)

The Domain Information Model (DIM) designed by Continua creates the information model for the measurement device and its data. The model consists of five classes (Figure 13):

1. Medical Device System (MDS) includes the agent configuration data, e.g.:
 - manufacturer, model
 - unique device identifier
 - configuration being used
 - list of "device specializations" that the device implements (e.g. "Weighing scale" or "Glucose meter")
 - time handling capability
2. Metric is an abstract base class for measurement data. E.g., classes Numeric, Real-time sample array and Enumeration are inherited from the abstract base class. Numeric-type is used typically to store and transfer single measurement values (e.g., weight). Real-time sample array type can be used, e.g., for storing a heart rate measurement session. Enumeration can include, e.g., annotations explaining the measurement result.
3. PM-Store (Persistent Metric Store) is a mechanism for storing some measurement data on the agent device. The idea is to keep the latest measurement values (e.g., 255 weight values and timestamps) in agent memory till it gets into connection with a manager device again and can transfer the data to manager.
4. PM-Segment (Persistent Metric Segment) includes data from one measurement session (e.g. one heart rate measurement session data).
5. Scanner class optimizes data transfer by grouping data. PeriCfgScanner includes regularly sampled data, while EpiCfgScanner includes irregularly sampled data.

5.5 Authentication and digital signature

5.5.1 General

Authentication and digital signatures are essential building blocks of internet-based services. Authentication refers to the verification of the real or virtual identity of the service user while the digital signatures enable the verification of the source, integrity and non-repudiation of information. Due to the sensitivity of health information, these technologies are of particular interest to PHR services.

Authentication is based on checking of one or several factors. These are typically divided into three groups:

- something, which the user has (e.g. smartcard, telephone/SIM card, ...)
- something, which the user knows (e.g. password, PIN code, ...)

- something, what the user is (fingerprint, retina, DNA, ...)

Currently the authentication of the citizen in internet-based services is mostly based on passwords and PIN codes. Approaches based on smartcards or mobile phones are used widely in professional applications.

As the amount of services requiring user authentication is rapidly increasing it has become important to transfer authentication information between services. Between the so called *federated services* the user does not have to repeat the authentication procedure when moving from one service to another (single sign-on service, SSO). Federation is typically based on SAML specification by (Security Assertion Markup Language)⁵¹ by OASIS or the OpenID specification⁵². In Finland, the SAML protocol has been used for example in the HAKA⁵³ authentication system used by several universities and in the VIRTU⁵⁴ trust network of public administrations.

The digital signature is based on a pair of cryptographic keys. It is carried out by using the secret key stored e.g. in the user's smart card while the signature can be verified by using the public key available to anyone. A digital certificate verifies the binding between the key pair and their owner. A Public Key Infrastructure (PKI) supporting proper generation, management and delivery of the certificates is needed for legally valid digital signatures.

5.5.2 Citizen perspective

Reliable authentication is important due to the confidentiality of the handled information in PHR services. Two approaches in implementing PHR services can be identified:

1. PHR services, in which the user is authenticated based on her real name, and the personal identification information is stored in the service
2. PHR services, in which the user is authenticated by a selected alias name (pseudonym), and there is no need to store personal identification information in the service

The advantage of the first approach is that information can be sent from clinical applications - where the real identity is known - directly into the PHR. This is not possible in the case when a pseudonym is used in the PHR service, which reduces the available benefits. On the other hand, when using a pseudonym the risk of the misuse of information is lowered since the service does not know the true identity of the user.

The simple authentication based on a user name and a password can be used in both cases - either when using the real name or a pseudonym. In Finland, the stronger methods in use are the citizen certificate (available on the personal identity card) and bank passwords (TUPAS), in which cases the authentication is always based on the real name. The citizen certificate is based on PKI architecture and is provided by the Population Register Centre. In addition to authentication, it can be used for legally valid signing of documents. The citizen certificate has not spread into wide use due to the cumbersome process to get the personal certificate operational and the related costs for the citizen. In addition to the certificate a smart card reader has to be procured and installed.

⁵¹ <http://www.oasis-open.org/>

⁵² <http://openid.net/>

⁵³ <http://www.virtuaaliyliopisto.fi/data/files/tapahtumat/vvyop07/esitykset/linden.pdf>

⁵⁴ http://www.vm.fi/vm/fi/04_julkaisut_ja_asiakirjat/03_muut_asiakirjat/20081027ValtIT/05_Linden_virtu_2008_1120.pdf

Another approach is to store the citizen certificate on the mobile operator's SIM card, in which case the card reader is substituted by the mobile phone. This kind of "mobile certificate" has been tested in Finland, but it has not gained enough customers. Currently, mobile certificates are not available in Finland. However, it is still believed that mobile certificates may spread into large scale use if the process for purchasing and getting the certificate operational can be simplified. The operators have been trying to find a solution for this in co-operation with authorities.

Bank passwords have spread into large scale use in Finland as a means for authentication for internet-based services. The advantage of this method is that network banking services are highly popular and most citizens are accustomed to use the passwords for authentication. The service using bank passwords may even create signatures on behalf of the citizen. However, these types of signatures, generated within the service system, are not based on a PKI-infrastructure. They can not be considered legally valid signature in the sense required by law, since they are not based on an appropriately generated personal certificate.

From the service provider's point of view the problem in using bank passwords is that the service provider has to establish contracts separately with all banks. Furthermore, the TUPAS specification does not support federation between services, which would be important for service providers' mutual co-operation as relevant e.g. in the PHR ecosystem.

Vetuma⁵⁵ and Tunnistus.fi⁵⁶ services support public on-line services by aggregating the bank password authentication services of several banks and certificate-based authentication into a single authentication, signing and purchasing environment. This way the task of implementing the service will be easier from the service providers' point of view. It has also been planned to include federation capabilities to the Vetuma service, in which case the additional value to service providers and citizens would be considerably increased. The limitation of Vetuma and Tunnistus.fi services is that they are only available for public organisations and not for private companies.

A single username password pair released by the service provider to the citizen is a more simple approach compared to bank passwords and certificate-based authentication. The username and password can be disclosed in the context of a personal transaction with the citizen or they can be sent over ordinary mail. A frequently used approach is that the citizen has to use bank passwords for authentication for the first service usage session during which a service-specific password is defined.

The username password pair is considerably less secure than bank passwords, since the password does not change between sessions. Despite of this, many PHR services, such as Google Health, have selected this method, since the more secure approaches are not globally available.

Transferring authentication information between services has been recognized as an important development objective when aiming at services in global scale. Already now, federated services based on the OpenID⁵⁷ protocol are widely used. OpenID enables the service provider to outsource the responsibility of user authentication to a specific "identity provider", which manages user identities and passwords connected to them. Several OpenID identity providers exist. For example, a company offering PHR services may opt to accept the identities provided by an OpenID (e.g. from Google) service. Based on the OpenID, networks of trust are

⁵⁵ <http://www.suomi.fi>

⁵⁶ <https://www.tunnistus.fi/>

⁵⁷ <http://www.openid.fi/>

being formed allowing the user to move from one service to another without the need for re-authenticating herself. The SAML protocol supports similar type of SSO-functionalities that the OpenID in browser-based applications. Additionally, SAML can be applied more widely for interacting software components in a Web Service environment such as a PHR ecosystem.

The EU financed STORK project (Secure Identity Across Borders Linked)⁵⁸ addresses the challenges related to exchanging identity information. The activity is aiming at a European-level solution, which would enable the identities defined at national level to be used in other countries. The project benefits from a large group of participating administrations responsible for citizen identity management in several European countries. The problem is not merely in shortage of applicable technology, but in getting the appropriate actors in different countries to co-operate.

5.5.3 Healthcare professional's perspective

Authentication is increasingly carried out by using the healthcare smart cards and related PKI infrastructure provided by the National Supervisory Authority for Welfare and Health (Valvira). The healthcare professionals will need to have the healthcare smart card in order to use the national KANTA services and to sign information to be uploaded to the national EHR (KANTA) archive.

The healthcare smart card is issued by Valvira exclusively for use within the healthcare and social services infrastructure⁵⁹. It is not possible to use the card for authenticating the professional into a commercial PHR service e.g. in the situation where the patient allows the doctor to view her PHR content. In such case the professional would need to have a separate account in the PHR service.

5.5.4 Protecting information in the PHR ecosystem

The basic security requirements related to individual PHR services are similar to other internet-based services containing confidential information. This includes a reliable means for authentication, secure transmission method (https), secure server environment and application, and deployment of security policies covering e.g. management and maintenance processes.

The PHR ecosystem sets additional demands for security. In the multi-organisation environment it may be necessary to protect information contents e.g. based on WS-Security - specifications⁶⁰. Content protection addresses encryption of the information in addition to the connections protected by the https protocol. The WS-Security allows selective encryption and digital signing of information based on security tokens attached to the exchanged XML content. These tokens can be used in many ways in the PHR ecosystem. For example, the security token may confirm that the person related to the content has been reliably authenticated. Digital signatures confirm the integrity and non-repudiation of the information. Selective content encryption may be particularly useful in the case when information is forwarded through a chain of services and all involved services do not have identical needs and permissions to access the information contents.

⁵⁸ <http://www.eid-stork.eu>

⁵⁹ <http://www.valtteri.fi/>

⁶⁰ http://www.oasis-open.org/committees/tc_home.php?wg_abbrev=wss

Exchanging user's information between PHR services is particularly sensitive. For example, if a service is requesting a particular individual's information the service releasing information needs to trust that the requestor is acting according to the user's consent. Technical solutions exist for exchanging such consent. However, trust between the communicating services shall be established beforehand by agreements between the PHR service providers. Attention should also be paid to the user interface of services so that the user has full control on the PHR information and is properly informed about information transfers between services.

5.6 Open source

Utilisation of Open Source (OS) software has increased rapidly both in work station and server applications. Open Source software brings several advantages. Direct costs spent in software development are totally or partly avoided when software development and software localization is carried out in global networks of volunteers. The resulting software quality and security is potentially high since the code is under continuous inspection of a large number of developers. Probably, the most important advantage is that the dependency of the service provider (software buyer) on the software vendor is reduced. This "software vendor lock-in" has become a problem in many areas including healthcare, where the health service providers are stuck to using large and complicated software systems. Usage of OS software would allow more competitive markets and remarkable cost savings both in the software deployment phase and when developing new features.

Usage of Open Source software opens interesting possibilities for the development of PHR services. Reference implementations based on OS, e.g. concerning service interfaces, could serve as building blocks of commercial services and guide the development activities towards open and interoperable direction. In particular, the common services such as the PHR service directory should be based on open source software. This approach is highly relevant especially in the case when common PHR services are developed partly by public funding.

Developing the PHR ecosystem in Open Source is also an attractive approach regarding international visibility and partners, which are important concerning the evolution of a global scale ecosystem. An alternative to starting new development activities is to join in an existing Open Source framework, such as the Indivo community⁶¹. The PHR platform developed by Indivo is already used e.g. in the Dossier services⁶². Other possible communities are Eclipse (OHF-Project)⁶³, openEHR⁶⁴ and Open Health Tools⁶⁵.

⁶¹ <http://indivohealth.org/developer-community>

⁶² <http://www.dossia.org/>

⁶³ <http://www.eclipse.org/ohf/>

⁶⁴ <http://www.openehr.org>

⁶⁵ <http://www.openhealthtools.org/>

6 Ecosystem of PHR products and services

6.1 Ecosystem members

Identifying the various members in a PHR ecosystem is difficult. This is a result from problems in defining the scope of an actual PHR ecosystem. However, regardless of the scope used, the number of potential members and stakeholders is large and diverse. This results in many different ways of segmenting stakeholders and members in the ecosystem. One approach would be to use the perceived role a member or a stakeholder has as basis for segmentation. This approach also has its difficulties due to the complex relationships between various members of the ecosystem. As a result of these relationships, situations where a certain member has multiple roles and could therefore belong to more than one segment can occur.

Table 5 illustrates how the PHR ecosystem members can be segmented according to role. The segments and potential members illustrate the diversity within a PHR ecosystem with members representing the private, public and third sector as well as members coming in all different sizes. This diversity is a crucial element in the ecosystem's value creation process, as it facilitates the realization of synergies among various members as well as helps to achieve a sufficient consumer base.

Table 5. Segmentation of PHR ecosystem according to role.

<i>Segment</i>	<i>Role</i>	<i>Potential actors</i>
<i>Ecosystem leaders</i>	Ecosystem leaders have a central role as visionaries showing the way, in defining technical standards enhancing interoperability and in facilitating the diffusion and internationalization of ecosystem SMEs. The segment will most likely consist of PHR providers.	Fujitsu Services, Microsoft, Nokia, Pfizer
<i>Integrators / Enablers</i>	Integrators and enablers represent those members with potential to influence the launch and development of the PHR ecosystem. They do so by bringing together various stakeholder groups. They also have an important role in financing as well as creating ecosystem rules and regulations (setting the context).	The Finnish Innovation Fund (Sitra), the Finnish Funding Agency for Technology and Innovation (Tekes), Technical Research Centre of Finland (VTT), Association of Finnish Local and Regional Authorities, municipalities, hospital districts, ministries
<i>Service and technology providers</i>	Service providers create the true value of the PHR ecosystem through the services they provide. It consists of a diverse group of companies with a broad service offering including eHealth and wellbeing applications targeted at the end user.	Technology providers and a vast group of national and international eHealth service providers.
<i>Customers / Co developers</i>	This segment can include end users (consumers) and the financers of services (payers). Customers play an important role as co developers of services in the ecosystem and in doing so help in the realization of expected PHR service benefits.	Public & private health-care service providers, employers, insurance companies, citizens
<i>Marketers /Ambassadors of good will</i>	PHR ecosystem growth is highly dependent on the motivation of consumers to adopt new services. This adoption represents a significant change in healthcare from reactive to proactive. Realizing this will demand the collaboration of all stakeholders.	All stakeholders listed previously, patient organizations, media, politicians

Figure 14 shows the potential stakeholders in a PHR ecosystem. The core of the ecosystem consists of the PHR service providers and developers. Their customers are citizens in various roles and traditional healthcare service providers whose responsibility it is to provide healthcare services for citizens. Their customers are the payers of these services. It is crucial to notice that the potential value of a PHR is greater if it is tailored for both the citizen's needs and the needs of healthcare providers. As it has been discussed earlier, health information can be used for many purposes. The use of this information however, requires creating, sustaining and monitoring the rules in an ecosystem where health information flows freely (with consumer consent). Creating these rules will most likely require a significant contribution from the public sector.

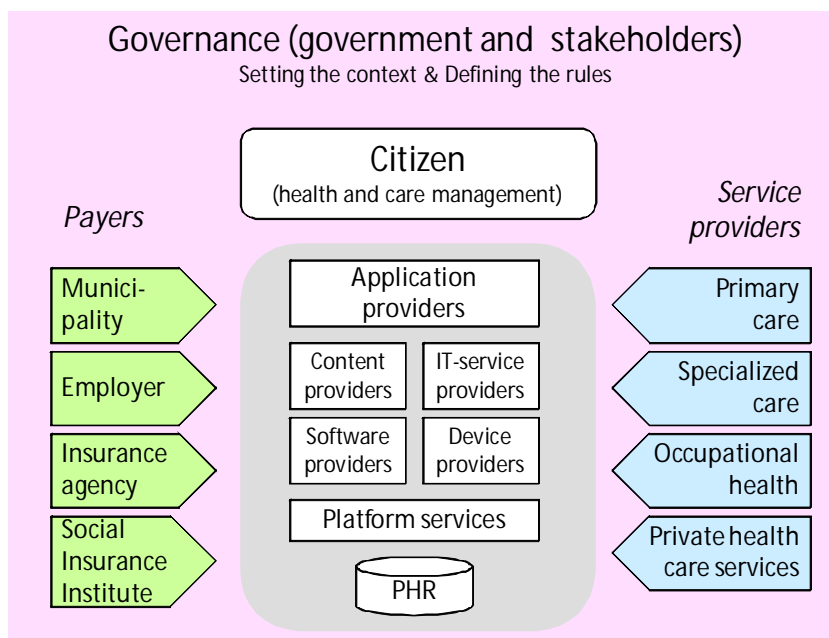


Figure 14. Stakeholders in the PHR ecosystem.

Another way of segmenting stakeholders is to make a distinction between whether or not a member belongs under the regulated healthcare services segment or under the market lead services segment (see Figure 15). This distinction has major implications on how a member is allowed to operate within the ecosystem. Healthcare professionals from the regulated healthcare services segment have an important role to play as part of the ecosystem (see Chapter 4.1). The business potential of many of the services, and eventually overall success of the ecosystem, is greatly dependent on how healthcare professionals adopt PHR services as a source of health information.

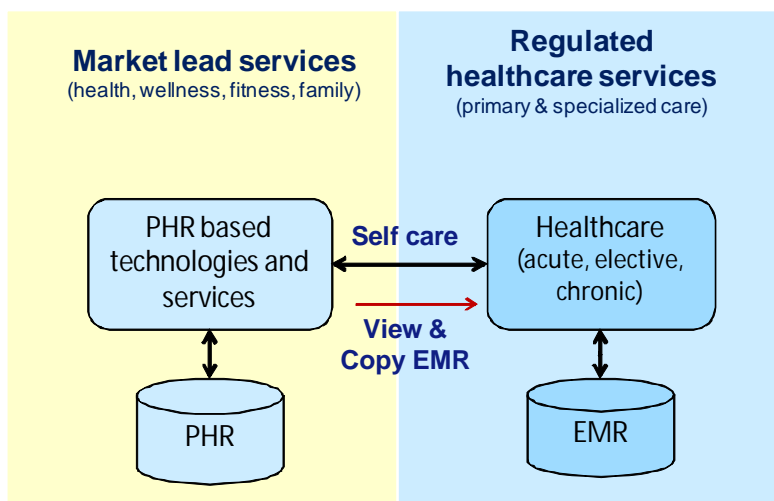


Figure 15. The public and market lead segments of a PHR ecosystem.

Members under the regulated health services segment include providers of special care, primary care, social- and health districts, private healthcare service providers and other health- and social care providers under regulation. The segment also includes those responsible of the regulation like the Ministry of Health (STM), the National Supervisory Authority for Health and welfare (Valvira) and the National Insurance Agency (Kela). The market lead service segment on the other hand mainly consists of companies providing services that enable citizens to manage and improve their own personal health and wellbeing. By including the regulated health services members into the PHR ecosystem an “information bridge” between

healthcare professionals and citizens is built. Before major breakthroughs are possible decisions must be made on what regulations are needed for the information flow between the two segments.

When defining the members of a PHR ecosystem, it should be noted that the goal is not to build national solutions but instead to build internationally competitive interoperable services. As a consequence the potential members in any PHR ecosystem should not be restricted to national players but instead seeking membership also from outside Finland. The ecosystem's goal should be cross border growth, which will lead to a wider service offering for consumers. From a service provider's perspective cross border ecosystems mean larger market potential. Achieving this will require agreements on international standards and probably common regulation and possibly even common legislation. An organization currently working to achieve this is Continua Health Alliance. Cross border ecosystems will eventually benefit all stakeholders as greater competition drives innovation faster than otherwise could be achieved.

6.2 Business models

The success of the ecosystem is highly dependent on the number of PHR service providers that want to take part in creating interoperable services. The minimum requirement is that these service providers agree to follow a common interoperable reference architecture (see 5.1). The main question then is how to launch the ecosystem? Will this be done by one or perhaps a group of motivated stakeholders and organizations that are followed by others? Or will the various stakeholders get organized perhaps in the form of a limited company and proceed forward as a legal entity?

There are two examples of PHR ecosystems that are taking form around ecosystem leaders, namely HealthVault (Microsoft) and GoogleHealth. Out of the two Microsoft is currently the clear market leader. This is due to Microsoft's general market position, as well as the fact that the HealthVault platform and the PHR is provided free of charge to consumers (and patients). Instead of user based charges HealthVault is financed by the advertising revenue it generates. GoogleHealth operates with the same business model. This particular business model seems to work well in the United States but could be problematic elsewhere. Application and service providers using these platforms will be required to follow the rules and guidelines set by these leading companies.

Another way to make a PHR service available is that a healthcare service provider broadens its offering to include a PHR and compatible PHR services. Examples of this model are the occupational health services provided by Dossia and the service offerings of Kaiser Permanente, Mayo Clinic and Veteran's Administration. This approach ties the PHR service user (citizen / patient) to a healthcare service provider. Although there are some signs in USA that healthcare providers might want to utilize HealthVault and GoogleHealth platforms for their PHR services. If that trend continues then citizens will de facto have a Personal Health Record that they truly own.

In Finland there are many public sector R&D projects going on side by side that aim at creating e-services for citizens. Some municipalities, like Oulu, are expanding the service offering towards PHR related services. Despite the Ministry of Health and Social Affairs efforts to coordinate development in the various R&D projects they are still fragmented and their development and procurement incentives remain unclear.

6.3 Customer segmentation

Table 6 illustrates some examples for PHR customer segmentation. The segments include age groups from children to senior citizens and potential payers from individuals to the public sector. The public sector's interests to pay for services will vary according to segment. The same applies to the individual. Parents can be willing to pay for the health of their children, as can children be willing to pay for the health of their ageing parents. The role of the payer therefore, changes during ones life. The health of an employee is the interest of the employer and insurance agency. The health of the unemployed on the other hand is the responsibility of public healthcare providers and the Social Insurance Institution of Finland (Kela). Despite the segment at stake, the offering PHR and PHR based services should be affordable, easy to use and motivating. This way the adoption rates of all segments will be higher and the possibility to realize expected PHR benefits on a large scale much higher.

Table 6. Examples of customer segmentation.

<i>Segment</i>	<i>Payer</i>	<i>Core service offering</i>
<i>Family Health Manager</i>	Individuals, relatives	Consultation services, health information needs, family health management, vaccinations, medication, hospital and primary care visits
<i>Independent living</i>	Individual, relatives, citizens, insurance companies, municipalities	Automatic alarm systems, medication reminders, device measurements etc.
<i>Worried Well</i>	Individuals, employer, insurance company	Health information about the effect of lifestyle choices on personal health and wellbeing
<i>Active Health</i>	Individuals	Services related to storing and analyzing measured health information, interactive networks for health knowledge transfer, consulting services, health information etc.
<i>Acute and elective health problems</i>	Individual, relatives, citizens, insurance companies, employers, municipalities	Services enabling the flow of health information to physicians when sudden health problems occur.
<i>Life style risks</i>	Individual, insurance companies, employers, municipalities (individuals may not be willing to pay)	Health information on the effects of life style risks (obesity and smoking for example) on one's health, peer groups etc.
<i>Chronic diseases</i>	Individual, insurance companies, employers, municipalities (all probably willing to pay)	Controlling medication, medication reminders, health information, peer groups, communication with healthcare professionals

6.4 Expected benefits of a PHR Ecosystem

The expected benefits of a PHR ecosystem can be viewed from several perspectives. The emphasis of benefits will also vary according to the development phase of the ecosystem itself (see Table 7). Before the ecosystem is up and running the most significant benefits have to do with ensuring the ecosystem's interoperability, sharing risk and achieving a critical mass of potential service providers, payers and consumers. Without a shared vision it is not possible to create standards leading to interoperability in PHR services at least on a large scale. In ecosystem centric development the problem of fragmentation can be avoided by building a larger ecosystem on top of the existing "miniecosystems". Instead of building separate information silos the ecosystem approach aims at building an environment based on a shared vision that

allows free flow of information with consumer consent. This free flow of information is a requirement for all scale- and synergy related benefits.

Before the ecosystem reaches a stable phase it enables sharing risk among various operators. Creating the ecosystem infrastructure requires both human resources and capital. An ecosystem approach enables sharing these costs. Cost savings can also be achieved from sharing R&D knowledge and avoiding doing overlapping work. This has currently been a major problem. Collaboration in R&D efforts should lead to faster innovation and building the ecosystem more quickly. Achieving a critical user mass will also require competitive collaboration. The major issue behind this is that in the beginning it is not a question of whose services succeed but rather does anyone's.

When the PHR ecosystem is up and running the ecosystem structure has clear business benefits. These benefits are a consequence of leverage and scale effects between various members. The synergy effects can realize from a broader service offering and the value chains the collaboration enables. The sum of different services working together is larger from the consumer's perspective than the purchase of individual services. The services in many cases should not viewed as substitutes but as complements. An example of this would be the collaboration of device manufacturer, a service provider and the provider of the actual PHR. The device enables certain measurements that can be analyzed through service provider's service and finally stored in the PHR with other related information. The device manufacturer has the choice of providing the service as well but in many cases better results can be achieved when all operators stick to their core competences.

Table 7. Potential PHR ecosystem benefits.

	Ecosystem benefits at start up phase	Ecosystem benefits while up and running
Business (Service Providers)	<p>A common vision speeds up ecosystem launch and facilitates reaching a better end result</p> <ul style="list-style-type: none"> • Securing scalability through technical and semantic interoperability • Shared risk, costs and knowhow • Facilitating ecosystem growth through shared marketing and R&D efforts leading to a broader service offering 	<p>Scale and synergy benefit enabled by leverage between service providers</p> <p>Increased value and increased demand through service bundles</p> <ul style="list-style-type: none"> • Larger potential for market penetration • Pooling resources allows concentration on core competences • Increased innovation potential • Global distribution channels through global leaders
Health and wellbeing (Consumers)	<p>No clear benefits during start up phase (Mainly B2B-"roll out", not B2C)</p> <ul style="list-style-type: none"> • The common vision enables development efforts that create the foundation for consumer benefits later on 	<p>Interpreability enhances functionality and availability while service bundles increase value</p> <ul style="list-style-type: none"> • A broader service offering leads to larger possibilities of realizing health benefits

From an individual service providers perspective the ecosystem can broaden its customer base through the various distribution channels the ecosystem provides. This should lead to additional revenue.

From a business perspective the greatest positive leverage effect to service providers comes from collaboration with those companies playing the role of the leader. These companies in the case of PHR will be global giants like Microsoft or Google. The global leaders can provide distribution channels to SME's to international markets and a pathway to ecosystems in other regions where the same global giant has a prominent role. Sharing resources is also a core benefit from this collaboration enabling smaller companies to concentrate on their core processes especially in fields like marketing and R&D. With R&D efforts especially the SME's risk is significantly lower due to a cost decrease resulting from pooling resources. Interoperability also has the same effect as the same R&D efforts can lead to market penetration in different geographical markets as well.

The ecosystem approach also benefits the end user, in this case citizens. The integration of services which occurs with an ecosystem approach results in synergies between different services. This synergy in many cases leads to more significant health improvement. A consumer's ability to find and being able to bundle services is also enhanced in an ecosystem. Integration plays a key role in offering citizens new ways to manage their health and care. A PHR alone will not achieve this. Technical and semantic interoperability also enables the continuous use of services regardless of where the consumer is located at any point in time. This improved availability of services is also critical.

Today, there is little evidence of these benefits actually realizing. Despite this, the international trend with PHR's is towards the ecosystem approach. If the benefits do occur, the PHR ecosystem can have a massive impact from a macroeconomic perspective. Eventually the approach (of engaging citizens to manage their health and care) could be the cure for the constantly rising healthcare costs. The business potential of the ecosystem is therefore vast.

6.5 Building the ecosystem

The core idea behind the launching a PHR and PHR ecosystem is achieving improvements in citizens' overall health. Through this it is believed substantial cost savings in healthcare costs can be realized. Achieving these benefits requires empowering citizens to more actively manage their own health and care. Simultaneously healthcare service provision focus would change from reactive to proactive in other words from curing illnesses towards prevention. The tools needed to actively manage ones health and care would be provided through the PHR and related services.

Achieving PHR benefits requires an ecosystem approach. The PHR itself will not change the health behaviour of citizens. Instead the PHR enabled services act as behavioural change drivers in facilitating the breakthrough of a new kind of healthcare system.

The adoption and diffusion of a PHR are dependent on many factors. On a general level the greatest barriers to quick diffusion seem to be the lack of mutual technical and semantic standards, PHR ecosystem regulation and solid business models. Seamless interoperability and collaboration between various stakeholders of the ecosystem will require common rules. From a customer's perspective there also needs to be proof of interoperability. Organizations like Continua Health Alliance are working to establish and implement such standards. So far no commonly agreed rules have surfaced. Out of the three current barriers technical interoperability is believed to be the easiest to achieve.

Regulation wise the PHR ecosystem is still in its infancy. Common rules through regulation can be seen as essential for the continuation of any kind of ecosystem level collaboration.

Will this regulation be national or international and who in the end is the one enforcing remains unclear.

From a business perspective an unclear factor is determining who the payer in various situations is. Calculating return on investment is difficult, which is a result from problems in quantifying achieved health benefits and their monetary value. Also the fact that any achieved health benefits reflected in cost savings will be spread between a number of stakeholders makes determining the payer more difficult. Before these financial incentives between stakeholders are aligned in some way it is hard to build an ecosystem committed to a shared vision.

As many questions do not yet have answers there are problems in coordinating the building and launching process of the ecosystem. Aligning stakeholder incentives with partially conflicting individual organizational goals is extremely difficult. This problem is further enhanced due to the fact that proving any potential ecosystem and PHR benefits requires taking the first step before there is clear evidence that any of the expected benefits actually realize. Evidence of benefits can be achieved through pilot studies, where the effect of certain PHR services is studied. However, the large scale gains expected from an ecosystem approach are hard to simulate in an artificial setting. From the ecosystem's stakeholders view stepping forward is about taking and managing risk. The breakthrough of PHR's and PHR related services is dependent on finding solutions to these obstacles that in turn will lower the risk to all those involved. The potential barriers blocking PHR breakthrough can be listed as critical success factors that need to be solved until a large scale breakthrough will be possible. These factors are shown in Table 8.

Table 8. PHR ecosystem critical success factors.

<i>Critical success factors</i>	<i>Description</i>
<i>Critical Mass</i>	Critical mass means achieving a significant consumer base for PHR's and PHR related services. Achieving this also requires a critical mass of services to be offered. A crucial matter is whether or not consumers feel the PHR and services answer an unmet need. Without this critical mass the structure of the healthcare system can not be changed from reactive to proactive.
<i>Trust, security and privacy</i>	In achieving a critical consumer mass trust, security and privacy are extremely relevant. Confidentiality matters concerning health information have to be followed by all service providers and before this can be done common rules and guidelines have to be set. Forcing these guidelines will require a higher level authority that initially enforces the guidelines and then monitors they are followed. Current and possibly new legislation also has a role to play in ensuring consumer trust.
<i>Evidence of benefits</i>	Long term success of the PHR ecosystem is dependent on whether or not the expected health and economic benefits realize. This may require major changes in current healthcare processes.
<i>Solid business models</i>	PHR ecosystem growth and service diffusion requires business incentives for service providers to engage in R&D efforts targeting new services and innovations. With potential benefits spreading to a large stakeholder base building a solid business case has been difficult so far. A positive ROI for service providers is necessary in the long run.
<i>Functionality and availability</i>	Realization of potential PHR benefits requires correct use of services. Service functionality and availability are key issues in achieving this.
<i>Aligned incentives</i>	Developing an ecosystem with a shared vision requires aligning stakeholder incentives in situations with potentially conflicting interest among various and within stakeholder groups. This requires building win-win situations where the sum of value created as a whole is larger than that of individual operators. While in theory this is easily said, in practice achieving this is far more difficult.

7 The context of the PHR ecosystem

In Finland three external activities have to be accounted for when planning for the PHR ecosystem launch:

- The national program for the EMR and ePrescription services
- National public sector eService initiative (Ministry of Finance)
- Integration with international activities.

7.1 Positioning against national eService initiatives

As has already been stated several times the PHR and EMR are complementary concepts (see Figure 16). The PHR is needed when transitioning towards a new health services landscape where citizens are given more responsibility in managing their health and care. The latter is needed in illness centered healthcare services both to document care and also for the operational improvement of the services. The important thing to notice is that neither the PHR nor EMR should be treated as archives where data is stored. Instead services should be created that make use of data to support citizens and healthcare professionals in decision making (cf. the Gartner CPR maturity model⁶⁶).

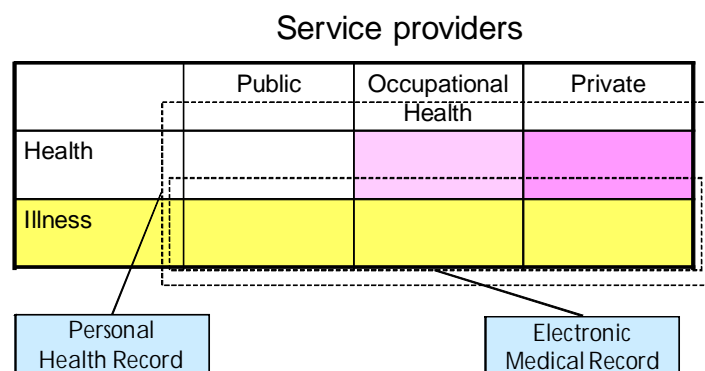


Figure 16. PHR and EMR are complementary.

The decision to build nationwide integrated EMR and ePrescription services was taken some years ago. Its implementation is ongoing and comprises three complementary activities: 1) setting up the centralized services, 2) modifying the existing EMR information systems in

⁶⁶ The Updated CPR Generation Criteria, Gartner Research, 2007, http://www.gartner.com/it/content/504500/504569/ks_hc_jun.pdf.

secondary and primary care to be interoperable with the services⁶⁷ and 3) interfacing the modified systems with the services (going live). All this is guided by an architecture plan of interfaces, data models etc. The services will also be accessible to citizens through a viewer application that will allow citizens to securely view their EMR. The implementation is behind its original time plan due to “all the normal reasons” of a program of this size.

Parallel to the EMR program municipalities and hospital districts have since many years been developing their eService portfolios. This has led to a multitude of web portals some developed locally and some procured from the market. Until now, there is not much interactivity in these services. Triage is another area where developments have been fragmented. Some have procured a Contact Centre service from the market, some have organized the service themselves, and some have not done anything to rearrange ambulatory services. In laboratory and imaging services centralized units have been created. But overall, the potential that virtualizing resources with ICT and especially with PHR related services offers, is far from fulfilled.

Ministry of Finance has been charged to be responsible for the IT sector policies and architecture of the public sector. Recently a special program has been launched, eServices and democracy (SADe)⁶⁸, through which public sector eService development will be coordinated.

The FeelGood consortium has made a proposal to the SADe steering group that PHR should be one of the first pilots.

7.2 Positioning against international developments – Testbed Finland

There is a lot ongoing on the international PHR front, especially in USA. Several large healthcare providers (e.g. Kaiser Permanente, Mayo Clinic, Partners Healthcare, Veterans Administration in USA and NHS in UK) are engaged in providing and developing PHR related services to their customers. Similarly major IT players (e.g. Google, Intel, Microsoft, Philips and as more recent additions Bosch and GE Healthcare) are investing in this market. Continua Health Alliance is the forum where the interoperability guidelines are being written. The development of applications and services is more fragmented. Pilots and RCT's are ongoing in several places to come up with evidence of benefits in using PHR and PHR related services.

Developments in the field can best be followed by participation in Continua's working group meetings. Of the conferences it is difficult to give any recommendations as the field is developing so quickly. One interesting recent development worth mentioning is the creation of the European Connected Health Campus⁶⁹ that organized its 1st Leadership Summit in May 2009. In June 2010 this will be coupled with the Continua meeting (“European Connected Health Week”).

The European Commission has also invested heavily into the development of this market. Policies across EU member countries are formulated through the eHealth Action Plan which since its launch in 2003 has been annually updated. In the Framework Program's ICT area they fund R&D projects in Personal Health Systems since some years. To encourage imple-

⁶⁷ As Finland has a nearly 100 % penetration of electronic patient information systems both in the public and private sector the modification task is large although the same interface standards and guidelines are followed by all.

⁶⁸ http://www.vm.fi/vm/fi/05_hankkeet/023_sade/index.jsp

⁶⁹ www.echcampus.com

mentations the Competitiveness & Innovation Program is used⁷⁰. Additionally through the Institute of Prospective Technology Studies (part of JRC) the Commission is seeking information on how the Personal Health Systems market is developing. This 3-year study has been named Strategic Intelligence Monitor – Personal Health Systems, SIMPHS⁷¹.

The Leadership Summit produced a Manifesto that outlined an action program for Connected Health. As part of that process two issues are worth highlighting. First the issue of evidence, it has been demonstrated that remote patient monitoring leads to decreased visits to ambulatory services (e.g. by Darkins et al [24]). But it does not automatically lead to cost savings. Based on the evidence in peer-reviewed journals that so far has been accruing the biggest challenge facing PHR is that benefits can only be obtained if current care processes, structures and reimbursement policies are changed. A different set of incentives are needed to make it attractive to providers to deploy PHR's and PHR based services. The other issue is that of pilots. Current thinking tends to focus on pilots that will produce the evidence that something works and lead towards full implementation. Dr. Martin Connor challenged that in the Leadership Summit and claimed that pilots in health-care never lead to results (see box above).

DROP THE PILOT, because

- They suffer from the problem of scope and 'Transferable solutions' don't transfer
- Solutions at scale are different in kind to successful projects
 - Because of risk (and therefore permissions)
 - Because of management resources
 - Because something will happen that will touch everyone -- this is scary
- If it's not about pilots, then what is it about?
 - It's about the top of the shop (first... to make the strategic offer authentic)
 - It's about the patients (nothing about me without me – populations too?)
 - It's about the data and information (frequency, quality, time lag)
 - It's about the doctors (for permission and insight... and when the going gets tough)
 - It's about the nurses and AHPs (the vanguard of the revolution)
 - It's about the general management (for project management, resources and assurance)
 - It's about the institutions (existing... and new?)
 - And...
 - It's about the vision thing...

Contacts with the international developments have in recent years been built through the health (technology) programs that Tekes and Sitra have been running. As a result of those processes and activities a more ambitious collaboration concept is in the planning, *Testbed Finland*. Its idea is based on the fact that due to our specific conditions, Finland could be a base for international companies in developing and evaluating new innovative solutions. An initial study in early 2009 confirmed the potential [23]. Currently, Tekes has contracted a consultant company to help it in coming up with a plan on how to launch this new activity in collaboration with other key Finnish national actors.

Having international members in the PHR ecosystem would naturally increase its potential. It would also create partnerships that would enable Finnish SME's to improve their international operations (from Testbed to Springboard). As an example one such Testbed case is currently ongoing. This TERVA project has been setup with Pfizer and some SME's in Finland and comprises of a large scale RCT study on the benefits of ICT based health coaching in managing CVD and diabetes (1000 patients + 500 control). The results will be available in 2010.

⁷⁰ Recently the Commission launched a tender process on a multi country large-scale-trial on remote patient monitoring. The winning proposal was named "Renewing Health" and is expected to start in early 2010. The Commission contribution to the costs of the project will be 7 M€

⁷¹ <http://is.jrc.ec.europa.eu/pages/TFS/sps.html>

8 Viewpoints and issues in the PHR ecosystem

8.1 Technical and semantic interoperability

The PHR service ecosystem consists of the following components (Figure 17):

- PHR repository that stores personal health data. Its structure should be based on technical and semantic standards as described in Chapter 5. There can be more than one repository in a PHR service ecosystem providing that these are interoperable both at technical and semantic level.
- Platform services that provide the required interoperability and trust services across applications and services using the platform.
- Applications that citizens, patients and healthcare professionals use.
- Devices that measure vital signs and other parameters and communicate with applications or the platform
- Multichannel communication means that allow the users to access and use the PHR related services according to need (phone, SMS, digital TV, web, ...)

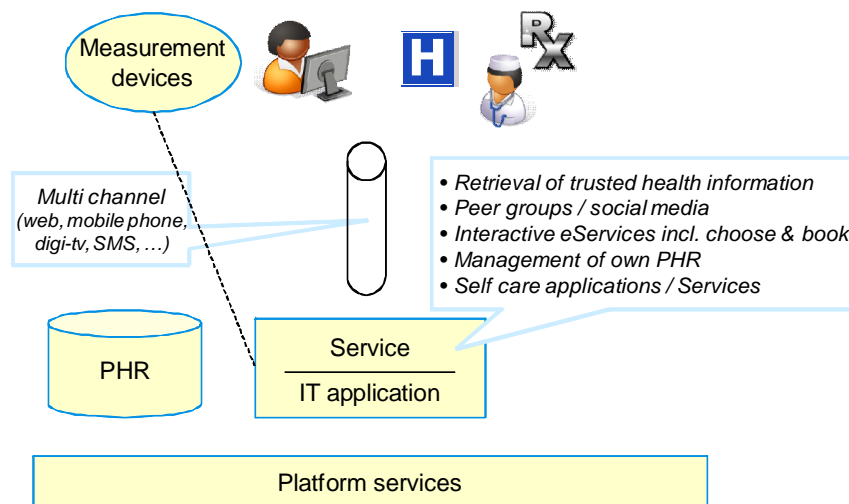


Figure 17. Components of a PHR service ecosystem.

The reference architecture described in Chapter 5 accommodates the integration guidelines of Continua and IHE. In reality though, Application developers have a lot of work to do in aligning their applications with the reference architecture requirements. However, it seems that the time for proprietary solutions is over. If a SME wants to succeed the first condition it that it follows international de facto interoperability guidelines. It also needs to be able to demon-

strate that its interfaces meets the requirements. This means regular participation into the Plugfest and Connectathon test events respectively organized by Continua and IHE.

In addition to technical interoperability it is also necessary that the data that are shared are semantically interoperable. In the case of personal health data there is still some work to be done before diary entries of items such as diet, quality of sleep, exercise etc. can be shared.

8.2 Mobility

PHR related services should be usable according to need, in principle "anytime & anywhere". In other words, the services should be available to mobile and stationary users. It has been shown that it is essential that the health and care management services can be used when the need arises. If management tasks must be deferred to a later time when the services are accessible the motivation to use them drops markedly. A key success factor is easy access with immediate feedback. Mobile technologies can provide such solutions. The challenge is to adapt the services to the performance and characteristics offered by mobile technologies.

Mobile technologies enable automation of data acquisition and when manual entries are required these can be entered on site (e.g. entries to a diet calendar in restaurant). When data acquisition works, the system can generate feedback to the user online (e.g. congratulations you've your daily exercise quota or a reminder at 20.00 hours that you are 15 min under your daily walking quota).

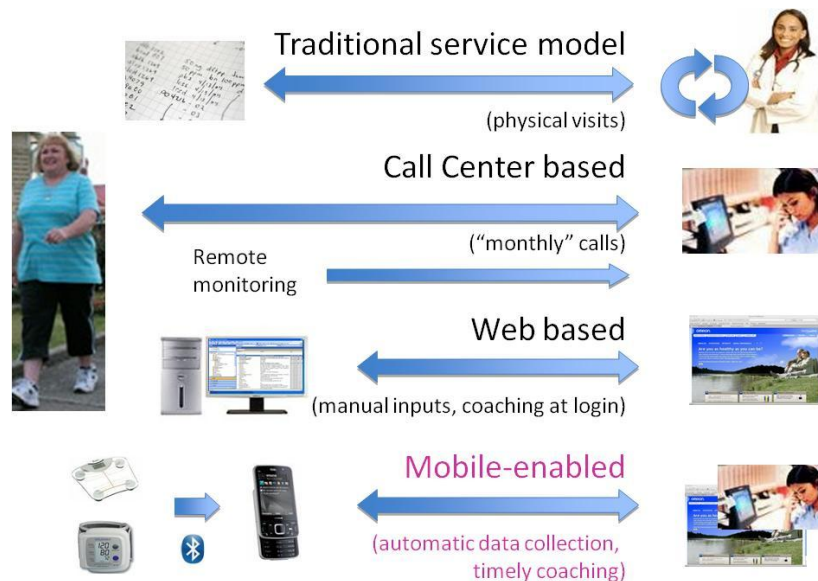


Figure 18. Mobility is an important extension in citizen centered PHR services.

Figure 18 illustrates the combination of different service modes that can be needed for a comprehensive service portfolio:

- "Self care" (health and care management) using web services, mobile technologies and measurement devices.
- Contact centers for health / care coaching combined with remote monitoring of vital signs and other parameters on a monthly basis
- Traditional physical visits to care centers based on a scheduled appointment

8.3 PHR services

The main components of a PHR ecosystem are the IT services (applications) that users use and pay for. These can be self contained (virtual) or embedded into a physical service provided by healthcare and other professionals. There are many ways to classify applications. In Figure 19 the classification is based on life stages. In Figure 17 the IT services were classified into five groups as follows:

- Retrieval of trusted health information
- Peer groups / social media
- Interactive eServices incl. choose & book
- Management of own personal health data (basic PHR services) and viewing & copying of own EMR data (from KANTA services)
- Self care (health and care management) supported by acquisition of vital signs and other parameters.

	Kindergarten	School	Employment	Retirement
• FamilyHealth Manager	Family Health Manager			
• Worried Well				
• Active Health				
• Acute health problems and elective procedures				
• Life style risks (list below)	Primary prevention			
• Chronic conditions (list below)	Secondary prevention			
• Independent living (list below)				

Independent living: Security, privacy, social contacts, daily activities at home and outside, mobility, communication, ...
Life style risks: diet, weight, MBO, genetic risk factors, lack of exercise, smoking, alcohol, drugs, stress, depression, ...
Chronic conditions: CVD, diabetes, COPD, asthma, ...

Figure 19. Classification of applications based on life stages.

A third way to classify is based how the services are offered to the users; freely in the market place or as part of the regulated healthcare services (in public and private sector). The three first rows of Figure 19 describe services that will be available in the market place:

- *Family Health Manager* refers to applications that assist a family member in managing all health related issues of a family. Depending on the life stage the focus can be children or (grand)parents. PHR services assist that person in the management task.
- *Worried Well* is commonly used concept to denote persons in their late middle ages who suddenly become aware that they should start worrying about their own or a family member's health. A life style change is what they are after and PHR related services can assist in starting and maintaining course.
- *Active Health* on the other hand denotes persons who are aware of that good health requires positive action and want to support and follow-up their progress with PHR related services.

The next three rows in Figure 19 describe services that will be available through the regulated healthcare services. Here the motivation to make them available to citizens and patients is that with them as co-producers of health better health can be obtained at less cost. These three

scenarios show clearly how the PHR and EMR services complement each other. The actions carried out by patients are documented into the PHR and the actions of the healthcare professionals in the EMR. For the full picture of a patient's health and disease the records must be combined.

- *In the after care of acute and elective procedures* rehabilitation is a critical element in the restoration of the functional capacity of a patient. Especially in Finland rehabilitation is not always done optimally. Acute and elective procedures are done in specialized care (hospitals) and after a brief recovery the patient is sent to home. Primary care in the patient's municipality has the responsibility to organize rehabilitation. There are communication problems in continuity care (transfer of responsibility) and limitations in available resources. Voluntary patient organizations therefore traditionally have been created to address some of these problems. PHR related services would allow a completely different way to provide personalized rehabilitation services to patients. The patient could be provided with a virtual (and when needed a physical) personal trainer that guides the patient in doing the required physical exercise. A good example to follow is what is being done in Australia for rehabilitation of cardiac patients⁷².
- *Life style related health risks* are usually detected in regular health checkups. At that time there is still time to intervene and thereby postpone the manifestation of a chronic condition. The problem, though, is that the person must make a major life style change and be motivated to maintain that change. The question then is how a person be supported in this? This boils down to a need to create and maintain motivation to lead a different life style (more of this in 8.4). PHR related services could be used to support the life style change and to provide feedback. The important thing to notice, though, is that "one size does not fit all". The services must be personalized to the needs and abilities of a person.
- *In the case of diagnosed chronic conditions* the scenario is very similar to the one described above. Patients need support in managing their care. Healthcare professionals support the patient but the main responsible is the individual. PHR related services will be useful in supporting self care. Also here the services must be personalized. One should notice that offering personalization can be a competitive advantage for application providers in the market place.

The last row *independent living* in Figure 19 covers the services described above and also those services that support the citizen in maintaining independence integration into society.

8.4 User needs, lifestyle and motivation

The seven most important risk factors for premature death are:

- blood pressure
- cholesterol
- Body Mass Index
- inadequate fruit and vegetable intake
- physical inactivity
- excessive alcohol consumption and
- smoking

Of these seven, six relate to diet and physical activity. Numerous scientific and dissemination documents have been produced with guidelines and recommendations for the management of the diverse clinical conditions associated with the presence or the development of an elevated

⁷² The Australian eHealth Research Centre, www.csiro.au.

risk profile. These documents have collected evidence from the most important clinical trials, in order to provide to the doctors useful and appropriate instruments to guide therapeutic choices, but they are often difficult to use in the daily clinical practice. The best therapeutic choice is guided by risk stratification, taking into account all the risk factors, not only the patho-physiological ones, but also the genetic, environmental, socio-cultural, behavioural and personal factors, in order to personalize the measures.

Therefore, in real life, implementation has proven to be rather complex because of several reasons.

- It is difficult to identify people at risk and assess their risks. People that are just at risk, with no co-morbidity, are not identified by the healthcare system in the traditional way. A much bigger part of the population could be incorporated if schools, workplaces, communities etc. could be included.
- Defining what are the adequate actions that the person must do or that have to be applied to the person to reduce her risk profile. This is a crucial issue, since, as the risk model becomes more complex and the action more personalized, the possibilities for interventions need to be boosted with the support of a dynamic and adaptive system. In this way, the needs of the individual and the desired lifestyle trends can be better aligned moving to a more personalized intervention than the traditional public health campaigns.
- Motivation is of importance when an individual is required to change the lifestyle she and her circumstances have chosen to follow. This change is normally neither easy nor wanted. To succeed in moving people towards healthier lifestyles there a joint and co-ordinated action is needed that includes all actors and mediators in school / workplace / community and family. In addition to this, any intervention should incorporate a strategy that contributes to the idea of convincing the person that the lifestyle change is required, and provides continuous feedback to support the permanence of those changes.
- Finally, there are sustainability and intrusiveness concerns. People at risk are in general terms healthy people that may be more or less aware of the consequences of not preventing risk but that for sure can't be expected to invest a great amount of resources in solutions with just a preventive background. In general people wouldn't like to be immersed in a highly intrusive environment that constrains their normal life. As a result, new business models, enhanced motivational strategies and innovative technological solutions are needed, involving non-traditional actors, and using products and services that are more consumer-oriented than health-oriented.

From experience we know that “one size does not fit all”. People are different, their life situations and motivations are different, diseases are different etc. This is especially crucial when we talk about primary prevention, as we are expecting healthy people to change their freely selected preferred way of life to reduce the probability of occurrence of a pathology that may never appear or that would have appeared in any case. In this line, primary prevention deals not only with a concrete medical condition, outlined in a personal risk profile, but also about the psychological attitude of the person towards this situation.

These boundary conditions make evident the need for a detailed user segmentation that allows maximizing the degree of personalization and the selection of the optimum strategy for each user and each situation in order to achieve the objective of “selling” the user a new way of life. And, in most cases, this user segmentation will have much more to do with behavioural economics and advertising that with a classification of medical conditions. Therefore different strategies are needed for different user segments, as behavioural economics and advertising literature clearly demonstrates. The question of course is how different these strategies need to be or in other words how much commonality there can be across them.

Table 9. A 3-D segmentation of users

Segment	Contents
By Diseases	Best practice & proven strategy for primary prevention
By Life Stages	E.g. neonatal period, early childhood, adolescence, reproductive age, middle adulthood, and older age
By Personal Profile	E.g. behavioural, life style and clinical (family history, biomarkers, ...) risk factors, socioeconomic status and education level

Table 9 shows one way for user segmentation. It comprises three dimensions. The first dimension is based on what is known about the prevention of a disease. The second dimension addresses the life stages of the users. Interests, awareness and needs are different in different life stages. The third dimension addresses issues that determine the personal profile of an individual. The best strategy (“the default”) surely would be that people just follow healthy lifestyles and are supported in this. For those that for various reasons are “not able / unaware / unwilling / don’t care” intervention strategies need to be constructed. Figure 20 shows another way to illustrate that the market for PHR based services needs to be segmented.

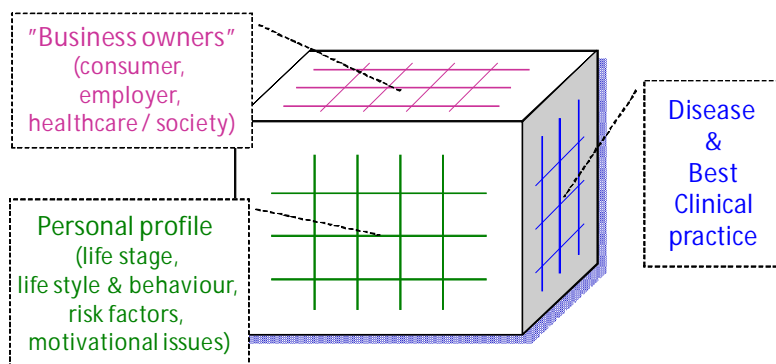


Figure 20. “One size does not fit all”, user needs, best practices and different business owners lead to a segmented market for PHR based services.

According to motivation theories motivation consists of three elements:

- a clear goal,
- an expectation to reach the goal and
- a right balance of enthusiasm and self control.

Goals shouldn’t be overly difficult to reach and they need to be concrete (tangible). The person must have a feeling that (s)he can do it, i.e. reach the goal. The pace of progress towards the goal is equally important. If the start is too fast and the results are not forthcoming quickly enough enthusiasm may wane. Similarly if enthusiasm is lacking getting started may prove too difficult. Feedback on progress is hugely important (“the carrot”). But what is often even more efficient is control by peers or other respected authorities (“the stick”). And then the change must be made part of the new life of the person, so that it becomes a consolidated habit that is maintained through time.

This is the theory. How does it apply to prevention? In secondary and tertiary prevention the person has a diagnosed condition and that alone is often considered to be a good motivator. And she has the support of healthcare professionals. But as experience has shown chronic patients are not very good in complying with instructions for a number of reasons. If compliance is poor in diagnosed chronic patients what can we expect with individuals who should take responsibility for their behaviour and lifestyle for primary prevention reasons? Especially

in the case of adults with well-established habits and behaviours there is a clear knowing-doing gap in what we know and how we conduct our lives. Sufficient information about healthy lifestyles does not translate into healthier lifestyles and behaviours and it is unlikely that more information alone would significantly improve the situation.

That people are irrational in their behaviour and choices is well known in marketing and advertising. Lately the work done in behavioural psychology and behavioural economics has been adapted to shed light into the behaviour of patients and individuals when facing health choices. Two books have been recently written on this (Predictably Irrational⁷³ and Nudge⁷⁴) that have received a lot of attention. The first of these is based on the fact that we are far less rational than standard economic theory assumes. However, irrational behaviours are neither random nor senseless. They are systematic and, since we repeat them again and again, they are predictable. The second book builds on this irrationality finding and suggests that choice architectures are everywhere and that a choice architect has the responsibility for organizing the context in which people make decisions. Consequently there are no neutral designs. If you are a doctor and must describe the alternative treatments available to a patient, you are a choice architect. A nudge then is what may be needed. These ideas have been shown to work in the consumer market. Would they be useful when applied to individuals in a primary prevention setting? Note that they challenge some already well accepted concepts in secondary prevention, such as the Chronic Care Model and Health Coaching (call centre outreach).

8.5 Security, privacy and trust

A key element in the PHR based service ecosystem is trust. If users do not trust the services they will not use them. An essential element in trust is that users feel assured that their private data is securely handled and that their privacy is respected. A number of laws and acts have been enacted that must be followed in handling personal data. In healthcare special regulations do exist on how EMR registries can be created, how they must be maintained and how disposed when no longer needed. Similarly access rights to a patient's EMR are regulated by special requirements.

At the moment there are no special regulations for PHR's. The question of course is that are special regulations needed? In practice, citizens' should be able to allow authorized people to view, write and change their PHR's. To implement such requirements technologies described in Chapter 5.5 above will be needed.

8.6 Proof of value and procurement

A central claim of the PHR based service ecosystem is that it will be possible to create health benefits at society level and also to provide more health with less cost. Proving this claim has so far been difficult. The currently ongoing health coaching trial (TERVA⁷⁵) in Finland seeks evidence through a large scale randomized clinical trial set up (12 months, 1000 patients and 500 control group) and has conceptualized a benefits chain as illustrated in Figure 21. The interventions (health coaching) lead to behavioural changes, which lead to improvements in clinical parameters and consequently less healthcare resources are utilized in the care of these patients and ultimately this leads to cost savings.

⁷³ Dan Ariely. Predictably Irrational: The Hidden Forces That Shape Our Decisions. HarperCollins 2008.

⁷⁴ Richard H. Thaler, Cass R. Sunstein. Nudge: Improving Decisions About Health, Wealth, and Happiness. Penguin Books 2008.

⁷⁵ www.sitra.fi/fi/Ohjelmat/terveydenhuolto/teho_hankkeet/Terveysvalmennusohjelma/Terveysvalmennusohjelma.htm

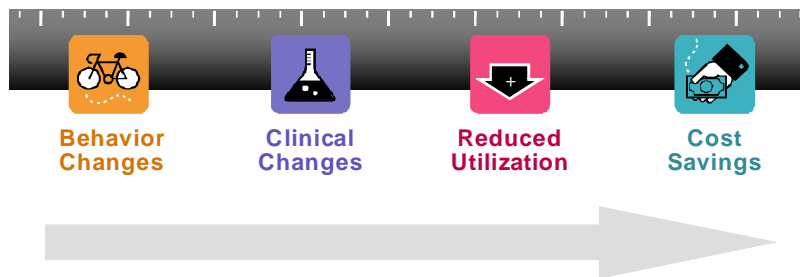


Figure 21. Accumulation of benefits (© Pfizer, TERVA)

The problem in obtaining evidence, however, is more complicated. A recent meta-analysis of TERVA like studies shows (Table 10) that indeed PHR based services will reduce the need for hospital visits and improves the health status of the patients. The challenge is in how these ICT based services are integrated into the functioning of the healthcare service provider. Therefore, today the biggest challenges lie in the procurement and deployment of PHR based services. Over the years pilots with varying degree of ambition have been run. The results show that health benefits can be achieved while the use of healthcare services is diminished. Actual cost savings, however, are difficult to demonstrate mainly because for these to materialize the current ambulatory visits based approach to manage chronic diseases should be replaced with an approach that optimally mixes self care and the services provided by healthcare professionals.

Table 10. Remote patient monitoring technologies create major changes in the use of ambulatory clinic services [24]. CHF = Congestive Heart Failure, COPD, Chronic Obstructive Pulmonary Disease, PTSD = Post Traumatic Shock Disorder.

Condition	# of Patients	% Decrease Utilization
Diabetes	8,954	20.4
Hypertension	7,447	30.3
CHF	4,089	25.9
COPD	1,963	20.7
PTSD	129	45.1
Depression	337	56.4
Mental Health, other	653	40.9
Single Condition	10,885	24.8
Multiple Conditions	6,140	26.0

Although the market so far has not moved very fast towards that direction there are signs that a change is forth coming. The first major signs were the creation of the Continua Health Alliance where the major initiative was with Intel followed by Google and Microsoft with their PRH based offerings. A further sign was the Manifesto that was drawn up in the 1st Leadership Summit organized by the European Connected Health Campus in May 2009. It identified the challenges as four complementary viewpoints⁷⁶:

- Governance
- Engagement
- Procurement

⁷⁶ <http://www.echcampus.com/news/events/leadership-summit.html>

- Implementation.

The procurement viewpoint is approached from a maturity angle. The main point is how well the procuring organization has thought through its needs and consequently how the solution which is being procured will support the organization in meeting its (business) objectives. In its simplest form the procurement process aims to acquire some technology and it is left for the organization to figure out how to deploy it. In its most complex form the procurement process aims to acquire a solution that will improve the health of the population that the organization serves. The core issue here is that technology is only a tool and it is up to the organization to figure out how to deploy it. In this context it might be useful to compare this with the so called four critical success factors in deploying ERP systems [25]:

- Business Case Development and Benefits Tracking (Identify and structure benefits, provide direction to project, identify business changes that are needed and decide on how to measure benefits)
- Business Process Management Skills (What do you want to do: (1) adapt the organization to the system that is being procured or to (2) to use the system to improve processes)
- Training (How much are you willing to invest: (1) Push-button classroom course or (2) real-life, one-on-one, end user training with attention to processes in order to overcome configuration & assimilation knowledge barriers)
- Change management (Pay attention to carrying out the changes needed).

The main message from these considerations is in order to reap the benefits you need to be ready to go through a change management process. The challenge that arises from this is that this will be most likely met with resistance to change from several stakeholder groups in the current healthcare system. The current incentives in most healthcare systems are based on patients visiting the professionals. The use of PHR based services translates into fewer visits to clinics and hospitals. The incentives must be aligned to support citizen and patient empowerment with virtualized resources.

9 Conclusions

PHR based services enable and support the transition of the current illness centered healthcare systems towards a service landscape where patients and citizens work in partnership with healthcare providers in health and care management (see Figure 22). The co-producer approach will enable proactive interventions at an early stage of disease development when the probability of full recovery is much higher and the required intervention resources much smaller than if the disease would have had time to continue its development.

There is a huge business potential in this new proactive health service landscape for all actors from device manufacturers, application developers, IT service providers all the way to the actual health(care) service providers. The barriers that are holding back this transition relate on one hand to the current structures in how healthcare services are organized and reimbursed and on the other in citizens having the abilities, tools and services to act in their co-producer role.

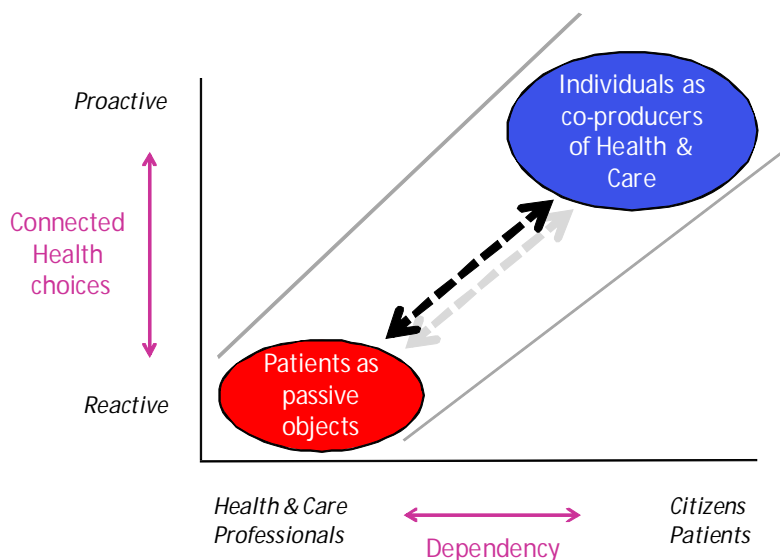


Figure 22. The Health Continuum viewed through the co-producer approach (© David Brunnen, European Connected Health Campus).

The PHR based service ecosystem consists of two segments (see Figure 15). In the other segment, regulated healthcare services, PHR services support and enable patients to act responsibly in their co-producer role and facilitate the dialogue between the co-producers. In the other segment, market lead services, PHR services enable citizens to manage their health and wellness. Both segments make use of the PHR repository and platform services that manage ac-

cess issues (security, privacy and authentication issues) and provide common services such as a service directory.

The PHR ecosystem partners and stakeholders have been identified. The question now is how the ecosystem should be launched. Quite a lot of applications are already available. There are also several partners that already provide a rudimentary PHR repository with platform services. There is interest in collaboration between the partners based on the reference architecture and open interfaces developed in the FeelGood exercise. What is missing is the market where the PHR ecosystem solutions could be sold. Or to put this in another way, the market today is highly fragmented. The idea of the ecosystem with a large enough volume of customers and transactions (a critical mass) is not there to be seen. Customers are buying solutions and services without a strategic view on how these can be used to improve their operations. This is largely due to the way healthcare is organized in Finland with each municipality being the responsible body for the citizens in that municipality. The potential that the PHR service ecosystem offers can only be realized when there are enough users in the system. What that translates into is a need to centralize current fragmented / distributed resources into service centers using ICT to provide the connectivity across place and time. In this highly fragmented situation some improved governance means are needed to bring the ecosystem partners together. One such possibility is the coordination that the government (Ministry of Finance) is trying to achieve through the SADe-program. That is why the FeelGood consortium made a proposal to the SADe-program that aims to bring the parties (supply & demand) together to launch the PHR service ecosystem.

The FeelGood road mapping process has shown that there is strong interest in the PHR ecosystem. We are strong in the technologies that are needed in this (mobile, devices, open interfaces). We have been active in the international PHR scene and development circles for some time now. It has become clear that especially in the PHR domain we need to build value chains with other partners in order to reach customers and provide value. International competition is already tough and will become tougher when the markets start to develop. Economies of scale will be important, but equally if not more so, important is that one can demonstrate the value of what is being offered not only in terms of health benefits but also in terms of cost savings. But getting to cost savings requires that the current healthcare incentives system is changed towards rewarding value-based health through proactive action.

Therefore although there is considerable interest towards the PHR service ecosystem it is not realistic to expect that this can be created by the actors themselves. We need strong support from the government to launch it. The government needs to be a partner in establishing the governance structures of the PHR ecosystem. We need to agree what regulations are needed to run the ecosystem and especially how the management of personal health data in a PHR repository must be handled. The incentives for healthcare providers towards value-based health need to be created. In the companies the incentive to take care of their human resources (HR) is already there. The benefits that can be accrued relate to improved productivity and decreased insurance premiums. In the public sector the biggest challenge relates to reorganizing the management of chronic diseases based on the co-producer approach. For this to happen government involvement is needed. Finally, although a lot is already available as devices, applications and services this does not mean that the R&D phase is over and done with. What is now needed is a coordinated action plan that puts the ecosystem in place and also encourages investments in new and improved applications. Putting the ecosystem in place ideally could take place with SADe funding combined with R&D funding from Testbed Finland.

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