Online electronic services for preventive and customer-centric healthcare

Experiences from PHR deployment in the Tampere region, Finland

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Health

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Preface

This report is part of the Wedge of Cranes (WoC) project (Kurkiaura in Finnish) carried out in the Tampere region within the time frame of January 2011 – October 2015. The project addressed the need to change the healthcare system towards a customer-centric model by adapting care paths according to the needs and capabilities of the patient. Such an approach requires the rearrangement of care processes and the deployment of supporting ICT tools.

This report considers personal health records (PHRs) as tools empowering citizens to engage in self-care. It introduces the main concepts related to PHRs and highlights their role in disease prevention. It also addresses some of the technical aspects – particularly from the interoperability perspective – and highlights key legislation concerning the implementation and use of PHRs. The report describes the PHR procurement and deployment activity carried out during the WoC project in the form of a use case demonstrating the PHR development process. As such, the report is intended to provide useful information for anyone working with PHRs, patient portals and self-care systems – in particular the professionals responsible for purchasing and implementing such systems.

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Abstract

1. Introduction

Population aging is a common challenge all over the world. In developed regions of the globe 23% of the population is now over 60 years of age, while this figure is predicted to reach 33% by 2050[1]. At the same time, healthcare costs are increasing, now amounting to around EUR 18.5 billion in Finland (9% of GDP)[2]. It is commonly accepted that a transition is needed from conventional reactive healthcare to preventive healthcare in order to meet the challenge of an aging population and rapidly rising healthcare costs. The objective of preventive healthcare is to keep individuals healthy by guiding them towards healthy lifestyles (primary prevention) and to prevent the recurrence of diseases (secondary prevention). In both cases, citizens must be empowered to enable them to take more responsibility for their own health. This implies a need for change in the healthcare process and mindset. Healthcare professionals at all levels need to support and encourage patients to engage in self-care as appropriate, while taking account of each patient's personal capabilities and motivation.

The Wedge of Cranes project (WoC)[3] (Kurkiaura in Finnish) addresses the above-mentioned need for change in the healthcare system. The project was completed within the time-frame January 2011 – October 2015, with the core idea of adapting care paths according to the needs and capabilities of the patient. Such an approach requires the rearrangement of care processes and the deployment of supporting ICT tools. The WoC project brought together the parties responsible for patient care paths in the Tampere region[4]: specialised care providers (Pirkanmaa Hospital District, TAYS Heart Hospital, and Valkeakoski Regional Hospital), primary care providers (the City of Tampere and Municipality of Lempäälä) and third sector service providers (the Finnish Heart Association and Hämeenmaa Heart District). The Hämeenmaa Heart District (a subsidiary of the FHA) coordinated the WoC project. VTT provided technological expertise for the project and contributed to concept development and results evaluation. The management

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[1] World population ageing 2013, United Nations:
http://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulation
Ageing2013.pdf
[2] THL,Terveydenhuollon rahoitus 2013, https://www.julkari.fi/handle/10024/125775
[3] http://www.kurkiaura.info/
[4] http://www.pirkanmaa.fi/en

group of the WoC project included representatives of all of the project partners. The group was led by the Ministry of Social Affairs and Health and included a representative of Tekes as the project's main financer.

The WoC project involved the definition and implementation of three ICT tools in support of patient-centred processes:

- **"Competent Patient"** (Osaava Potilas in Finnish)[1] is a web-based rehabilitation programme for patients recovering from a major heart operation.

- **"Health Radar"** (Terveystutka in Finnish)[2] is a web-based service for finding health-related services and events.

- **"Navigator"** (Suuntima in Finnish)[3] is a questionnaire-based tool for finding the most appropriate care path, service components and ICT-based tools, given the capabilities, preferences and clinical condition of the patient.

- **"Health Pocket"** (Terveystasku in Finnish)[4] is a personal health record (PHR), which enables the citizens to access and manage personal health-related data and to use related online services.

The WoC project approached heart patients as a specific pilot group. However, all of the tools used were generic and applicable to other patient groups. The Health Radar and Health Pocket is expected to be equally useful among healthy persons (primary prevention).

This report addresses personal health records in general and from the perspective of Health Pocket. PHR is an important building block in empowering citizens to engage in self-care in the context of both primary and secondary prevention. For individuals, this provides a way of accessing and managing essential health-related data. Additionally, a PHR may include versatile tools such as decision support for the patient, risk tests, disease and health-related lifestyle information and tools for communication with healthcare professionals [1].

The objective of the report is to provide useful information for anyone working with PHRs, patient portals and self-care systems – in particular, those professionals responsible for purchasing and implementing such systems. We will provide a general overview of PHRs from various perspectives and describe the Health Pocket PHR development and deployment phases performed within the framework of the WoC project.

Chapters 2–4 mainly provide a generic treatment of the issue and do not focus on certain processes or the infrastructure of the Tampere region. Chapters 5–7 are based on experiences obtained within the context of procurement and deployment activities during the WoC project. We have tried to present the results in a generic manner, which enables their exploitation in other contexts.

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[1] http://www.sydan.fi/omakuntoutus
[2] http://www.tampere.fi/terveystutka/
[3] http://www.kurkiaura.info/Suuntima_demo/
[4] https://www.terveystasku.fi/

We will begin by outlining the role and benefits of PHRs in primary and secondary prevention in Chapter 2. Chapter 3 will then present the technological aspects, including PHR architectures and commercial products. In Chapter 4, we will briefly address the related legal and regulatory issues. Chapter 5 provides a description of the procurement and deployment process of a PHR. In Chapter 6, we will describe the set-up and results of the Health Pocket evaluation study. Finally, Chapter 7 and 8 present discussion and conclusions.

2. Role of personal health records in disease prevention

2.1 Personal health record types

The Medical Library Association defines a personal health record (PHR) as ([1], [2]):

> *"A private, secure application through which an individual may access, manage, and share his or her health information. A PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. A PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR. PHR sponsors include vendors who may or may not charge a fee, health care organizations such as hospitals, health insurance companies, or employers."*

As indicated above, a PHR does not eliminate the need for an EHR, which provides the official tool used for care documentation. On the other hand, in countries, where EHR systems and infrastructures are not yet well established, a PHR may be a substitute for an EHR [3] or convey clinical information between healthcare organisations[1].

In many cases, a PHR is an integral part of a healthcare provider's electronic health record system or online patient portal, in which case it is referred to as a **tethered PHR**. Such services have been available from public and private health service providers for some time in Finland and abroad[2,3] [4], [5]. One success story is Kaiser Permanente's tethered PHR solution, My Health Manager, which has attracted 4.9 million registered users out of a total of 9.6 million Kaiser Per-

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[1] https://www.healthit.gov/sites/default/files/consumer_mediated_exchange.pdf
[2] http://www.informationweek.com/healthcare/patient-tools/9-popular-personal-health-record-tools/d/d-id/1103871
[3] http://www.sum.dk/~/media/Filer%20-%20Publikationer_i_pdf/2012/Sundheds-IT/Sundheds_IT_juni_web.ashx

manente patients[1]. The disadvantage of a tethered PHR is that it is bound to a certain healthcare service provider and available to the individual only as long as he or she continues to be a customer of the provider. A tethered PHR also lacks support for the continuity of care paradigm [6] when several organisations are contributing to the patient's care path.

Alternatively, an **interconnected PHR** exposes open interfaces to other systems, which are trusted based on certain quality criteria. The advantage of interconnected PHRs is that they can, in principle, be connected to all EHR systems containing the individual's health data. The best-known interconnected PHR solution and ecosystem on a global basis is Microsoft's HealthVault[2]. There are also ecosystems such as Fitbit[3] and Withings[4], Apple Health Kit[5] and Samsung Digital Health[6], which are specifically targeted at supporting mobile health apps and health monitoring. Validic[7] is a platform for connecting up information from devices and other systems with a broader scope than mere health monitoring. Taltioni[8] is a Finnish PHR platform that provides a common data repository for health and wellness services and which can be connected through open interfaces. Although, technically speaking, interconnected PHRs can be connected with EHRs, this has not yet occurred in practice. Instead, healthcare providers have mainly established tethered PHR's for the use of their patients.

There is some variability in the scope of PHRs. This is sometimes determined by the information content stored in the PHR. Additionally, the term usually covers functionalities allowing the user to manage (e.g. view and update) the information content of the PHR. The term, personal health record system (PHR-S), may be used to refer to the technological platform rather than the PHR content. Furthermore, advanced software components may be connected to the PHR for purposes such as data analysis and providing automatic feedback for the user [7].

Above, we highlighted the tethered and interconnected PHR approaches. Stand-alone and local PHR models are also possible [8]. For example, a PHR may be implemented on a smart card or mobile application for the sole use of the owner. While such PHRs may be simple to use and implement, their disadvantage lies in their lack of connection with other systems. They therefore have limited value in the context of the healthcare process. The importance of connecting PHRs within care processes and EHRs has been highlighted in several studies [9].

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[1] http://share.kaiserpermanente.org/static/kp_annualreport_2014/
[2] https://www.healthvault.com
[3] http://www.fitbit.com
[4] http://www.withings.com
[5] https://developer.apple.com/healthkit/
[6] http://developer.samsung.com/health
[7] http://validic.com/
[8] http://taltioni.fi/

2.2 PHR in preventive healthcare

Preventive healthcare divides into three categories [10]. **Primary prevention** includes methods of avoiding the occurrence of a disease (e.g. immunisation, healthy diet, physical exercise, smoking cessation). **Secondary prevention** addresses methods of halting or slowing the progress of a disease (e.g. treatment of hypertension, cancer screening). **Tertiary prevention** seeks to manage and soften the impact of complex, long-term health problems (e.g. rehabilitation after surgery).

The data contents provided by PHRs can be useful in all three categories of prevention. The contents of a PHR can be categorised in accordance with Table 1:

- **EHR information** is clinical information stored in the form of documentation on care and used by healthcare professionals. Although clinical data is stored in the EHR system primarily for the needs of clinicians, it is also commonly understood as being valuable to the patient, to whom it should be accessible through the PHR. For example, granting the patient access to laboratory data can considerably enhance care processes involving anticoagulants. In general, access to EHR data improves the patient's understanding of his/her health status and diseases, thereby increasing the potential for self-care. Additionally, EHR information can be exploited by the patient's decision support tools, which provide the patient with automatic messages and guidance.
- **Documents** refer to a collection of various types of health-related documents ranging from public information on diseases and their prevention to personalised guidance documents on self-care. PHR is a natural distribution channel for providing patients with personalised guidance material in particular. Public health information is typically distributed through the public section of the patient portal. It may also be relevant to store links to such material in the PHR, where individuals can find it easily.

Self-measurements include the results of measurements and symptom-observations performed by the patient. Typical monitoring parameters are shown in

- Table 2. Depending on the disease, all of the listed parameters are of relevance in secondary and tertiary prevention (disease management). With respect to primary prevention, the most typical monitoring parameters are weight, physical activity and other life-style related observables.
- **Questionnaire forms** are an important mechanism for conveying information from the patient to the healthcare organisation. A typical example of this would be the collection of background medical information from a patient before treatment in hospital.
- **Patient's decision support** refers to a set of tools providing the patient with automatic (computerised) guidance. Such guidance may be a virtual health check which involves the provision of an overall health status as-

sessment based on patient's replies to a questionnaire [11]. In the context of secondary and tertiary prevention, the patients' decision support may consist of computerised feedback messages based on self-measurements. Decision support is sometimes sufficient for solving a patient's problems; in other cases the patient is instructed to contact health professionals.

- **Messaging** between patients and health professionals constitutes an efficient interaction channel. From the healthcare provider's perspective, this feature is a challenging one since it requires the resources of healthcare professionals. Processes must be redesigned in order to create a properly organised reply service.
- **General information** on health and wellness usually forms part of PHRs, but as public information it tends not to form part of the content of the PHR itself, but is at the end of a link to another source.
- **Personal profile** data refers to basic personal information such as the contact information of the patient and personal preference settings.

In addition to the PHR information groups listed in Table 1, appointment booking is sometimes considered a PHR service. In most cases, however, it is considered a separate online service which can be accessed from the PHR via a hyperlink.

Table 1. Typical contents of a PHR.

Data group	Description	Source data	User interface functionality
EHR information	Care plan, diagnoses, risks, medication, laboratory results, referrals, discharge summaries, appointments, encounters.	Transferred from the EHR system or entered manually by the customer.	Information viewing. Insert complementary information.
Documents	Care instructions, medical certificates…	Stored manually by healthcare professional or customer.	Download, upload and viewing (e.g. pdf).
Self-measurements	Self-measurements, observations, notes, …	Entered by customer or automatically transferred from measurement devices.	Web forms for adding and managing entries. Display of data in tables and graphs.
Questionnaire forms	User questionnaires (pre-arrival and feedback forms etc.).	Filled in independently by the customer or as requested by the healthcare professional.	Functionality for filling in and managing web forms.
Patient's decision support	Intelligent tools providing personalised and context-aware guidance for the customer.	Data stored in the PHR system and specifically requested from the customer.	Interactive web forms providing textual and visual outputs for user guidance.
Messages	Messages between the customer and healthcare professional.	Message contents entered by the customer and healthcare professional.	Web forms for writing, reading and managing messages.
Task list	List of tasks or notes.	Created by the customer or a healthcare professional.	A list showing tasks or notes. Functionality for managing the list (e.g. add new tasks).
General information and links	Public information and links on health and wellbeing.	Entered and maintained by healthcare provider's personnel.	Pages and frames with information and links.
Personal profile and settings	Customer's basic information and personal service settings.	Partly retrieved from other systems (master data) partly entered by customer.	Web form for entering and editing data.

Table 2. Typical monitoring parameters in self-care.

Monitoring parameter	Measured quantity	Primary prevention	Disease management	Examples of diseases
Blood pressure	Systolic and diastolic BP [mmHg] Heart rate [1/min]	x	x	Hypertension, type 2 diabetes (T2D), …
Weight	Body weight [kg] Waist circumference [cm]	x	x	Hypertension, heart failure, T2D, …
Length	Body length [cm]	x	x	Child growth disorders
Physical activity	Energy consumption, step count (e.g. based on accelererometry)	x	x	Heart diseases (rehabilitation)
Life-style	Notes on usage of alcohol, cigarettes, nutrition, physical exercise	x	x	T2D, cardiovascular diseases, cancers
Blood glucose	BG [mmol/l] (before/after meal)		x	Diabetes (Type 1 and Type 2)
Spirometry	Peak expiratory flow (PEF) [l/min], Forced expiratory volume (FEV) [l]		x	Chronic obstructive pulmonary disease (COPD), asthma
Oxygen saturation	SpO_2 (pulse oximetry) [%]		x	Chronic obstructive pulmonary disease (COPD)
Symptoms and pain	Subjective observation based on disease-specific classifications		x	Heart failure, cancers, mental health
Independent living compliance	Falls detection, motor and cognitive performance		x	Musculoskeletal disorders, Parkinson's disease, Alzheimer's disease
Medication use	Automatic medicine dispensers control and track medicine intake		x	Diseases with drug therapy (especially for elderly patients)
Sleep	Heart rate, respiration, sleep cycles, sleep time (e.g. based on ballistocardiography)		x	Sleep disorders (e.g. sleep apnoea)
Anticoagulation therapy	Prothrombin ratio, International normalised ratio (INR)		x	Cardiovascular diseases

2.3 PHR as part of the care process

A PHR can be used independently of healthcare services in various ways. For example, an individual can record and monitor weight and blood pressure trends.

Independent PHR use is highly relevant to individuals with elevated health risks who are motivated to engage in lifestyle changes. In the case of individuals for whom a chronic disease has already been diagnosed, it is highly desirable that PHR be used interactively, alongside healthcare professionals, as part of the care process. For example, in the management of blood sugar levels or the monitoring of blood pressure, access to monitoring data is useful to healthcare professionals [7][12]. In this way, some regular control visits to health clinics by chronic patients can be avoided. Additionally, a PHR improves the flow of information before and after control visits, thereby making such visits more effective.

From the health professional's viewpoint, the use of PHR data differs from that of an electronic health record (EHR), which is the everyday tool for care documentation and information access. A PHR can contain inaccurate information and the health professional must evaluate the data's usefulness and reliability before using it as a basis for care decisions. However, it should also be noted that many care decisions and plans are based on subjective information given by the patient. Information provided by electronic means should therefore be exploited and valued during the care process in the same way as any other information disclosed by the patient. In fact, information stored in the PHR by the patient is likely to be more accurate than information that he or she remembers and communicates to a health professional during an appointment. When data from the PHR is used in the care process, for example as the basis of a prescription, the appropriate documentation should be created by copying a PHR extract into the EHR, with annotations by healthcare professional.

In the case of a tethered PHR, practices related to use of a PHR in care processes can be easily defined, since the PHR is set up and configured by the organisation. With respect to the exploitation of different PHR solutions and wellness tools on the market, the situation is more complex. Little support is available for healthcare professionals in choosing and recommending such tools for their patients. Few services are currently available which provide support in selecting wellness applications: such services include My Health Apps[1] and NHS Health Apps Library[2], which provide a ranking of wellness applications based on healthcare professional reviews. Whitelisting of this kind is an important part of the so-called "application prescription" approach. Application prescription can be considered a "recommendation" for a patient to use a particular application, with an anticipated positive health outcome[3]. The idea behind application prescription is not new – it has previously been used in the recommendation of exercise programmes for patients [13].

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[1] http://myhealthapps.net/
[2] http://apps.nhs.uk/
[3] http://medicaleconomics.modernmedicine.com/medical-economics/content/tags/2014-ehr-scorecard/physicians-guide-prescribing-mobile-health-apps?page=full

2.4 PHR usage by citizens

A recent Finnish study addressed the use of electronic citizen services, including some tethered PHR services (My Kanta and Hyvis) [14]. The related data was collected in 2014 and includes responses from 4,015 citizens. According to the results, 16% of citizens had occasionally used the national PHR service (My Kanta). Occasional use of a local PHR service (Hyvis) varied in the range of 4–16% in the area covered by the service. The relatively low values are due to the fact that these public services are still in their early development phase. For example, at the time of the questionnaire the My Kanta service provided full access to ePrescription data, but covered only a small part of patient record data. Variability between regions in the proportion of citizens who occasionally used the service was high: from 7–36%. The study [14] did not cover PHR services in the private sector, which are more widely available and used by customers. In Denmark, PHR services have been available for citizens for a decade. According to a recent study, 55% of citizens had logged into the sundhed.dk portal to search for their patient data (e-journal) [15].

2.5 Health outcomes

Active use of a PHR can correlate with positive health outcomes. In general, the possibility to access and manage personal health-related information is expected to increase the individual's interest and capabilities in health maintenance, which is likely to correlate with healthier lives. In particular, positive effects could result from better control of chronic conditions based on the possibility to monitor health parameters and take corrective action. Monitoring parameters such as weight and exercise activity may also be helpful in the primary prevention of diseases.

Evidence exists on the positive effects of health monitoring as part of chronic disease management. Positive results have been reported in the case of life-style dependent diseases such as hypertension and type 2 diabetes (e.g. [7] [12] [16]) in particular. However, several studies have been unable to demonstrate quantifiable health outcomes (e.g. [18] [17] [19]). The evidence on health benefits is particularly vague in the case of heart failure, although it has been predicted that the potential economic benefit would be high [20].

The outcomes of health monitoring in terms of the primary prevention of cardiovascular diseases are difficult to demonstrate, since the benefits may only be quantifiable after several years have passed. Successful interventions based on mobile phone applications have been reported in the cases of smoking cessation [21] and the reduction of risky alcohol use [22]. Mobile apps may also play an important role in resource-limited settings. In addition, promising results have been reported in terms of using SMS messages to remind people to take their medicine [23].

3. Technical aspects

3.1 PHR-EHR architecture

Personal health records form only part of the IT infrastructure required for the provision of health services. To be efficient, such an infrastructure should comprise interoperable systems, and the related work processes should be well-defined and harmonised in order to realise the benefits of technology. Coordination at a higher national and international level is needed in order to guide development towards these goals. In Finland, the Enterprise Architecture (EA) methodology has been applied to the harmonisation of architectural approaches and specifications for the development of ICT based services [25]. Such harmonisation has been targeted by the SADe programme[1] (The eServices and eDemocracy acceleration programme), which involves the development of eServices for citizens.

A comprehensive review and fine-grained classification of PHR architectures is presented in [8]. A review of Finnish PHRs and visions of the related national architecture is provided in [26]. Cloud-based PHR architectures are specifically addressed in [24]. For the purposes of the present study, we will focus on the connections between PHRs and EHRs, which have been considered the key challenge by earlier studies [9]. Such a connection is relevant at data level (to enable the exchange of health related data) and at authentication/authorisation level (to enable access by professionals using an EHR to access the PHRs used by their patients).

The term PHR-EHR architecture is used below to highlight the role of the two types of PHR (interconnected and tethered) and their connections with EHRs and other systems. Figure 1 presents a generalised PHR-EHR architecture. While corresponding to the current situation in Finland, it is also aligned with infrastructures in several other countries. The architecture includes the following components:

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[1]   https://www.thl.fi/fi/web/thlfi-en/research-and-expertwork/projects-and-programmes/the-social-welfare-and-health-care-service-entity

- **EHR systems**. Healthcare providers typically have their own electronic health record systems. Depending on the country in question, different approaches are taken to enabling communication between the EHRs. Such systems can be based on a national EHR archive as in Finland [28], or on distributed architectures as in Canada [29].
- **National or regional EHR System/Archive**. An EHR system providing a national or regional-level patient record system or archive, in which information from health providers' EHR Systems is stored.
- **Patient portals**. Online systems, by which the customers of healthcare service providers can perform actions required for the arrangement of care (e.g. booking appointments and filling in forms) and can access various types of information (both public and personal) related to their health. Patient portals typically include tethered PHRs integrated in various ways with the corresponding EHR system of the service provider. In addition, a national or regional EHR can provide a patient portal, such as the "My Kanta"[1] service in Finland.
- **Interconnected PHRs**. PHR systems – independent of individual health providers – providing access to lifelong records of personal health-related information.
- **Third-party health and wellness applications**. Applications and services used by individuals for health maintenance, for managing a chronic disease, or in the context of a care episode.

A tethered PHR – a component of the patient portal – provides a storage location where a patient can access and manage his or her personal health-related information sourced from online transactions, appointments and other interactions with the health service provider. Interconnected PHRs play an important role in aggregating information from all of the patient portals used by the individual and facilitate connectivity with third-party applications. Such connections are needed in order to ensure continuity of care and the possibility to fully exploit the rapidly growing ecosystems of web-based and mobile applications.

Standard interfaces are necessary in order to enable information flows between components. Such interfaces can be roughly divided into three categories: interfaces between two EHR systems (EHR-EHR IF), interfaces between two PHR systems (PHR-PHR IF) and interfaces between an EHR and a PHR (EHR-PHR IF). Figure 1 highlights the fact that the patient portal, interconnected PHR and third-party applications are separate entities provided by different organisations. The standard interfaces between such entities facilitate data collection from different sources, to be accessed by the citizen through a single user interface. For

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[1] http://www.kanta.fi/en/omakanta

example, the patient portal can integrate data retrieved from interconnected PHRs and third-party applications. The role and functionality of these three service entities and the PHR-PHR interface is discussed in the following sections.
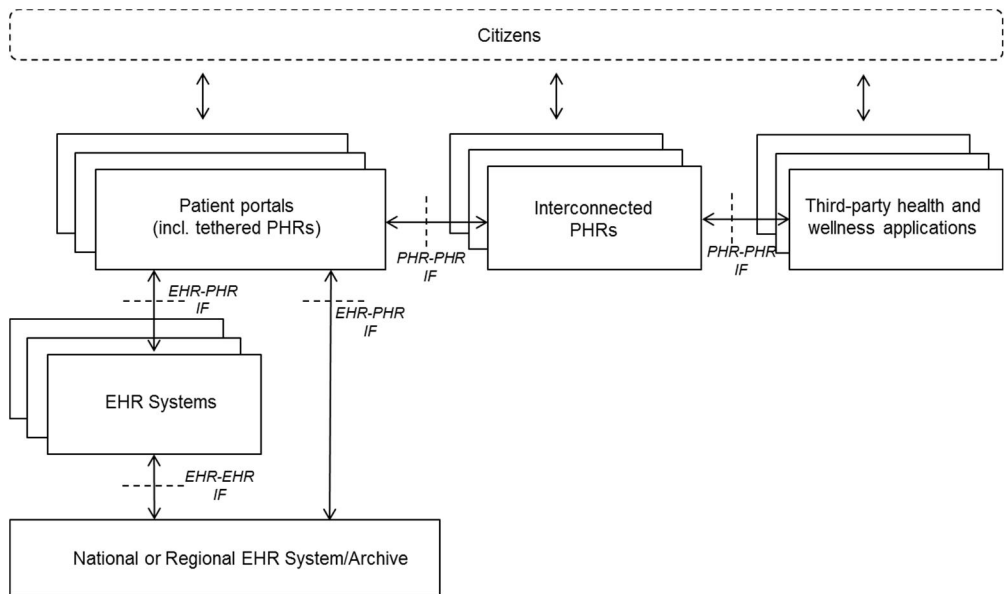
Figure 1. Overall PHR-EHR architecture.

3.2 Patient portal

A patient portal is a channel enabling direct interaction between a health provider and its customer. As such, it typically includes both public and personal information content. Examples of public content include information on healthy lifestyles, prevention, diseases, clinical operations, contact information of health services, risk tests, discussion forums, healthcare provider's organisational information etc. Personal service components include messaging, appointment booking, questionnaires, personal instructions, uploading of health monitoring data and access to personal clinical data (e.g. laboratory data).

The patient portal can form an integral part of the service provider's EHR System. Alternatively, the patient portal can be a self-standing service component open to integration with the EHR system. The advantage of the former approach is that the patient portal and the EHR system form a solid entity, which can lead to a better user experience for healthcare professionals and more efficient data management. On the other hand, the latter approach leaves greater freedom to choose an appropriate product matching the service provider's requirements. Modern EHR systems are shipped with open Web Service interfaces, which ena-

ble the integration of patient portals and other service components. Legacy EHR systems have not been designed to be interoperable: connecting them to the patient portals of other vendors has proven costly and time-consuming.

Patient portals are traditionally service-provider specific. In the private sector, this is logical from the business perspective: healthcare providers consider patient portals a useful instrument for building customer relationships and are therefore reluctant to share them with competitors. In the public sector, healthcare service providers have traditionally deployed their own information systems (e.g. EHR systems) in support of service provision. This tradition has been strengthened by legislation which, in Finland for example, sets constraints on health provider organisations in accessing patient data across organisational boundaries. However, in many countries shared patient portals are emerging among public healthcare providers. In Finland, a good example of this is the "Hyvis" service[1], a joint service between seven public healthcare provider organisations in southern and central Finland. The motivation for joint portals is based on the possibility of sharing costs between organisations and providing better service for healthcare customers. For example, in a case where the customer can freely select his or her healthcare provider, it is convenient if the same portal can be used across several providers.

Another global trend is the emergence of centralised services (e.g. national EHR archives) enabling country-wide access to clinical documents. Such services are typically based on national legislation and often include a patient portal for citizens.

3.3 Interconnected PHR

Interconnected PHR refers to a PHR which is not associated with a particular healthcare provider, but provides open interfaces allowing it to be connected with several EHRs and other sources of personal data. Such functionality is needed, as in most cases the patient consumes health services provided by different providers during his or her lifetime, which means that an interconnected PHR is required for data collection and the formation of a holistic picture of the individual's health status. In most cases, interconnected PHRs are provided by entities other than healthcare providers. On the one hand this is an advantage, since the PHR provider can be a neutral partner for health service providers, which may be competing with one another. Additionally, the PHR provider may have better competences and the motivation to develop innovative services matching the user's needs. The challenge lies in the lack of a clear business model for an interconnected PHR. Furthermore, many health service providers still avoid this approach and have not established connections between their EHRs and interconnected PHRs.

However, there are positive signs that the level of interoperability is improving. For example, the Epic[2] EHR provides open interfaces, which can be used by external applications for exchanging patient data with the EHR system. A driving

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[1] www.hyvis.fi
[2] https://open.epic.com

force behind interconnected PHRs may lie in the increasing interest in the use of apps and gadgets for personal health monitoring. Health service providers do not have the required skills and motivation to integrate such applications with their patient portals. Instead, interconnected PHRs can easily retrieve data from personal health monitoring systems. Consequently, health monitoring can be fed into patient portals via the interconnected PHRs serving as "filters" and "aggregators" of the monitoring data.

3.4 PHR interfaces

3.4.1 General

Open interfaces are needed for the exchange of information between the services depicted in Figure 1. Exchanging information between two EHR systems (EHR-EHR interface) is already a well-established and widely used approach. In this section, we will study interoperability from the perspective of PHR-PHR and EHR-PHR interfaces, which are most relevant to PHR system development.

We will consider interfacing based on the Service Oriented Architecture (SOA) paradigm, through which data is exchanged between two communicating entities: a provider and a consumer. This approach enables "loose coupling" whereby communicating entities require only minimum knowledge of each other. Such an approach is particularly useful when information is transferred between different organisations, which is typically the case in PHR-PHR and EHR-PHR integration (Figure 1).

The protocol layers of interest are depicted in Figure 2. On the transport and data structure layers generic (not healthcare-specific) protocols are exploited. The HTTPS (Hypertext Transfer Protocol Secure) protocol ensures end-to-end protection of the data connection. At the data structure level, XML (Extensible Markup Language) data structures are most typically used, although increasing use is being made of more compact formats, such as JSON (JavaScript Object Notation) in mobile applications, for example. Messaging and content layer standards are covered in the following sections.
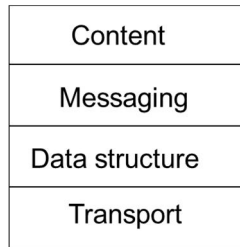
Content
Messaging
Data structure
Transport

Figure 2. PHR interface layers.

3.4.2 Messaging layer

The messaging layer utilises the underlying transport layer and provides a means of exchanging structured data between entities. SOAP (Simple Object Access Protocol) is extensively used in service oriented architectures and EHR systems. It provides the generic "envelope" with the necessary address information and information required by the recipient for interpreting the contents. In the context of SOAP, Web Services Description Language (WSDL) is commonly used to define the functionality of web services to which SOAP messages are sent.

SOAP and WSDL are applicable to EHR-PHR and PHR-PHR interfaces and have been applied in many cases e.g. the open web service interface of the Finnish Taltioni PHR service. In terms of lightweight PHR applications, interfaces based on the REST (Representational State Transfer) architectural style have quickly emerged as an alternative to SOAP. These so-called RESTful web services are not based on a detailed standard in a way similar to SOAP. Instead, RESTful web services allow SOA services to be constructed more freely based on a wide range of standard technologies. For example, RESTful web services are not limited to XML-based contents, but can exploit JSON structures, which are less verbose and can be more easily processed with software languages used in web-based and mobile applications.

The SOAP envelope can carry healthcare specific messaging such as HL7 messages. The HL7 v2 and v3 standards are extensively used in healthcare systems for exchanging messages related to the clinical process, e.g. for resource booking. HL7 messaging can be applicable to tethered PHRs, which may be closely bound to clinical processes [31]. However, due to the associated complexity and implementation costs, HL7 messaging is not largely used in the context of PHRs. This is particularly true of interconnected PHRs, which are expected to provide robust and simple interfaces that are only loosely bound to clinical processes at organisational level.

3.4.3 Content layer

The content layer deals with the definition of the personal health data content, which is attached as the payload in the "envelope" provided by the messaging

layer. Standardisation of the content layer is most critical to the PHR interfaces, since a common language is needed for all of the connected applications to be able to exchange meaningful data. In relation to the lower layers, it is appropriate to allow parallel use of standards. For example, an interconnected PHR service can support several alternative messaging protocols such as SOAP and RESTful web services.

Several standards were originally designed for exchanging semantic content between clinical systems [30][32]. The Clinical Document Architecture (CDA) developed by HL7 is an expressive document standard widely used for exchanging EHR data. Release 2 (CDA R2) [33] of the standard is used in the Finnish Kanta EHR archive. CDA and other "full" EHR content standards can be adopted for PHRs, but the use of patient summary standards is more often preferred. These standards have been designed for the purpose of providing extracts of EHR data on the continuity of care. As such, they are more appropriate for PHRs since they cover a compact set of relevant data and are easier to implement. A good example is the Continuity of Care Document (CCD), which is based on a set of constraints related to the CDA specification. As a result of a joint effort by HL7 and ASTM, the standard has been harmonised with another existing patient summary specification, the Continuity of Care Record (CCR). Both CCD and CCR are supported by several interconnected PHRs, including the HealthVault by Microsoft. CCD also forms the basis of Bluebutton+ services, which provide healthcare customers with access to their EHR records[1] covered by the U.S. Meaningful Use Stage 2 requirements. Furthermore, the patient summary of the European epSOS system [34], intended for the mediation of patient documents across countries, is based on CCD. For health monitoring purposes in particular, HL7 has defined another CDA-based content specification, Personal Health Monitoring Report (PHMR), which has also been adopted as part of the Design Guidelines of the Continua Health Alliance.

While HL7 v3 standards (including CDA R2 and CCD) are highly sophisticated and expressive, they are also considered to be difficult and complicated to implement. The Fast Healthcare Interoperability Resources (FHIR) specifications[2] are targeted at providing a more easily implementable alternative. FHIR builds on a base set of resources (data structure definitions) which, either by themselves or combined, satisfy most user needs. Combined with RESTful web services, FHIR has proven efficient in remote monitoring scenarios [35].

The medical content standards referred to above provide the data models for describing health data. Such data models also provide support when attaching clinical codes to data items. Clinical codes are used to establish a common understanding of clinical procedures, diagnoses, medicines, laboratory values and procedures. Coding systems such as SNOMED-CT, ICD-10, ATC and LOINC are extensively used in EHR systems but, due to semantic interoperability requirements, clinical codes are also expected to play a growing role in PHRs. Clinical codes also facilitate automatic language translation, which is an attractive option in

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[1] http://bluebuttonplus.org/
[2] http://www.hl7.org/implement/standards/fhir/

cross-border health applications[1] [36]. The challenge concerning semantic interoperability of PHRs lies in the large variety of health and wellness data they cover. Such data, relating to issues such as physical exercise, is not always covered by existing clinical coding systems. The vocabularies required for describing PHR data may exist, but more work needs to be done on formalising and standardising them [37].

As described above, there are existing medical content standards that are applicable to PHRs. However, such standards do not yet cover all developer needs, entailing that many PHRs and related applications are based on product-specific data models. Such a trend is undesirable, since it is complicating the connectivity of PHRs. The positive side is that, although product-specific, many PHR interfaces are open and enable connection with other systems[2,3].

3.5 Integration profiles

Integration profiles are frameworks which define the transactions required in certain commonly needed tasks and recommend applicable standards for their implementation. The integration profiles of the IHE (Integrating the Healthcare Enterprise)[4] are widely used for managing the complexity of clinical systems and are also applicable in the context of PHRs. Continua Health Alliance (CHA) leans on IHE profiles in providing interoperability specifications particularly aimed at connecting self-care devices to healthcare infrastructures. In Denmark, a national architecture for collecting personal health data has been defined based on CHA and IHE/XDS specifications[5].

A recent study tested the use of IHE profiles and CHA Design Guidelines in the context of PHRs. The overall observation on the applicability of IHE and CHA specifications was positive, although the currently available mobile platforms may lack some of the required functionalities [38]. The challenges are related to the fact that IHE profiles have strongly relied on the use of SOAP and XML, which is not the most optimal technology for mobile applications. The new IHE profile (Mobile access to health documents, MHD)[6] will improve the situation by supporting the use of RESTful web services and JSON.

It should be noted that CHA Design Guidelines have been created from the perspective of connecting devices to repositories, such as EHRs and PHRs. Concerning the architecture depicted in Figure 1, it is important to note the existence of PHR data – which needs to be transferred between systems – alongside devices and measurement data. For example, the contents of questionnaires (e.g. risk tests) are highly variable and are mainly not covered by international standards.

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[1] http://decipherpcp.eu
[2] https://msdn.microsoft.com/en-us/healthvault/healthvault.aspx
[3] http://taltioni.fi/yrityksille/#palveluiden-kehittaminen
[4] http://ihe.net
[5] http://www.ssi.dk/English/HealthdataandICT/The%20National%20eHealth%20Authority/Standardisation/ReferenceArchitecture.aspx
[6] http://wiki.ihe.net/index.php?title=Mobile_access_to_Health_Documents_(MHD)

3.6   Security

Due to the sensitive nature of personal health information, account should be taken of a number of security and privacy issues in the provision of PHRs and PHR-based applications [39]. The confidentiality of personal information must be maintained both during transfers between service components and during storage. The need to share personal data with healthcare providers and other trusted organisations or individuals poses a specific challenge to security mechanisms [6]. PHR privacy is briefly discussed in Section 4.

The overall security of the PHR consists of a combination of several perspectives, including application security, information technology security and security policies. Application security refers to the protection of an application from external threats. Listings of security vulnerabilities (e.g. OWASP[1]) are commonly exploited during the application development phase in order to ensure secure application design. Key vulnerabilities include flaws allowing an attacker to enter malicious code into database queries (injection flaws), to compromise credentials (broken authentication and session management flaws), or to induce the server accept malicious code to be sent to the user's browser (cross-site scripting flaws).

Good design and coding practices (e.g. proper treatment of input data and encryption of data) are needed to protect systems from the multitude of potential attacks. Increasingly, open source web frameworks and toolkits are used in application development. This approach adds the benefits of community-based detection and the fixing of vulnerabilities of software components. In the case of applications transferring confidential user data, a basic security measure involves using the HTTPS protocol (Hypertext Transfer Protocol Secure) and a server certificate to protect the information channel. HTTPS handles the encryption of the transferred data by using the SSL (Secure Sockets Layer) or TSL (Transport Layer Security) protocol. Identification of the server being connected is provided by a server certificate.

Information technology security (IT security) refers to the computer system on which the application is running. In the context of web-based PHR, it would be relevant to consider the security of the entire server system, including computers and generic server software. Such services are typically purchased from external service providers. From the PHR providers' perspective, the key issue is to select a reliable provider and ensure that the terms of service provision are clearly documented in the service contract.

Security policies refer to the processes applied by the organisations involved in the service offering or development. They are of high importance since security precautions of a high-quality application are easily bypassed if the appropriate security policies are missing or not followed. A key standard in this domain is ISO 27799, which provides guidance to healthcare providers and other holders of personal health information on how to protect personal health information.

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[1] https://www.owasp.org/index.php/Main_Page

4. Regulatory and legal aspects

The relevant legislation concerning personal health records and other ICT-based wellness services divides into two groups, as listed in Table 3. Generic laws address the privacy of the individual (data subject) using a service containing and processing his or her personal data. The primary legislation in this respect is the Personal Data Act, which is based on the European Data Protection directive[1]. This act defines the obligations and responsibilities of the service provider (data controller) in order to guarantee the safe management of personal data and the data subject's rights e.g. to obtain information on stored data content. In addition, the Act on the Openness of Government Activities stipulates that individuals have a right to access official documents pertaining to themselves. Other generic laws address requirements related to electronic identification services and the interoperability of information systems. These laws do not impose direct requirements on PHR systems. However, they include obligations which affect the overall infrastructure of ICT-based services and should therefore be taken into account in the design of PHR systems.

The healthcare-specific laws listed in Table 3 address the rights of patients and set requirements for healthcare infrastructures with the aim of guaranteeing the availability of patient data in the context of clinical care delivery. For example, these laws include stipulations on the handling, management, disclosure and preservation of clinical documents. Clinical documents are defined as "documents or technical records used, drawn up or arrived when the treatment of the patient is arranged and carried out and which contain information on his/her state of health, or otherwise personal information about the patient"[2]. The transmission of clinical documents from EHRs to other systems, such as PHRs, can occur with the consent of the user. It is important to note that, in such a case, only a copy is transferred to the PHR, while clinical documents are always stored and maintained in the clinical information system, e.g. an EHR, as official care documentation.

Some uncertainty currently surrounds the legal status of copies of clinical documents transferred to a PHR, since the legislation in force does not lay down an

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[1] Data Protection Directive of the EU: http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:31995L0046&from=en

[2] http://www.finlex.fi/en/laki/kaannokset/1992/en19920785.pdf (Act on the status and rights of patients)

explicit definition of a PHR. A PHR could be interpreted as an extension to an EHR, in which case its contents could be considered clinical documents as defined under legislation. On the other hand, in accordance with the original concept a PHR should be information storage under the control of the individual concerned. In such a case, its contents should not be considered clinical documents as defined by legislation. For example, the archival of PHR content is not mandatory and a patient has the right to remove such copies from his/her PHR. This is analogous to a case in which paper copies of clinical documents are given or sent to the patient.

Healthcare-specific legislation is of high importance in a case where PHR data is accessed by healthcare professionals. The statute on clinical documents[1] obliges healthcare professionals to include all relevant information concerning the implementation and follow-up of care in an EHR [40]. This means that any use of data from a PHR in the context of healthcare delivery must be properly documented in the EHR in question.

Patient safety is another dimension addressed by healthcare-specific legislation. The Medical Devices Act is based on the corresponding EU directive[2]. The Act was modified in 2007[3]. According to the new version, standalone software (software without a clinical device) may also be covered by the directive, if the software is to be used for healthcare purposes. This is the case if the software has more sophisticated functions than plain storage, transmission and the display of results[4]. For example, personal health applications providing automatic feedback or decision support may be considered MDD Class 1 devices, by which is meant "medical devices with low risk". In such a case, compliance with MDD requirements must be self-evaluated by the software provider.

[1] Statute on clinical documents, http://www.finlex.fi/fi/laki/alkup/2009/20090298
[2] Medical Device Directive of the EU, 93/42/EEC http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CONSLEG:1993L0042:20071011:en:PDF
[3] Medical Device Directive of the EU (amended), 2007/47/EC. http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2007:247:0021:0055:en:PDF
[4] http://www.601help.com/Regulatory/mdd.html

Table 3. Key national legislation related to personal health records and online health services.

Finnish National Law		Key content from PHR perspective
Healthcare-specific laws		
785/1992	Act on the Status and Rights of Patients[1]	Patient's right to be informed and right to self-determination. Confidentiality of patient documents.
159/2007 (updated: 1227/2010)	Act on Electronic Customer Data handling in Social and Health Services[2]	Information management guidance, interoperability. National EHR archive (Kanta) and the related procedures (e.g. patient's consent). Citizen's access to data.
629/2010	Medical Devices Act[3]	Based on the EU's Medical Device Directive (MDD). Definition of a medical device based on its intended purpose. Classification of medical devices. CE-marking. Notified Bodies for certification.
1326/2010	Health Care Act[4]	Patient information registers and handling of patient data. Health and welfare promotion. Choice of treatment facility.
Generic laws		
523/1999	Personal Data Act[5]	Privacy of information. Handling principles of personal data. Public registers. Obligations and rights of the subject and the register controller.
621/1999	Act on the Openness of Government Activities[6]	Principle of openness. Publicity of official documents. Individuals' right to access official documents pertaining to themselves.
617/2009	Act on Strong Electronic Identification and Electronic Signatures[7]	Regulation for identification service providers, e.g. concerning the requirements for "primary identification" and the requirements for strong authentication.
634/2011	Act on Information Management Governance in Public Administration[8]	Guides public administrations to the improve interoperability of information systems (e.g. by using Enterprise Architecture frameworks).

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[1] http://www.finlex.fi/en/laki/kaannokset/1992/en19920785.pdf (Laki potilaan asemasta ja oikeuksista)

[2] https://www.finlex.fi/fi/laki/ajantasa/2007/20070159
(Laki sosiaali- ja terveydenhuollon asiakastietojen sähköisestä käsittelystä)

[3] http://www.finlex.fi/fi/laki/alkup/2010/20100629 (Laki terveydenhuollon laitteista ja tarvikkeista)

[4] https://www.finlex.fi/fi/laki/ajantasa/2010/20101326 (Terveydenhuoltolaki)

[5] http://www.finlex.fi/en/laki/kaannokset/1999/19990523 (Henkilötietolaki)

[6] http://www.finlex.fi/fi/laki/kaannokset/1999/en19990621 (Laki viranomaisen toiminnan julkisuudesta)

[7] http://www.finlex.fi/en/laki/kaannokset/2009/en20090617.pdf (Laki vahvasta sähköisestä tunnistamisesta ja sähköisistä allekirjoituksista)

[8] https://www.finlex.fi/fi/laki/ajantasa/2011/20110634 (Tietohallintolaki)

Concerning the implementation of a PHR, it is important to assess its position with respect to privacy legislation. Table 4 lists the two different types of PHR in this respect.

Table 4. PHR types with respect to privacy legislation.

PHR type	Description	Relation to legislation
1. Anonymous PHR	PHR does not contain structured identification information related to the user	Personal Data Act does not apply.
2. PHR with person identity	PHR contains structured identification information related to the user. The PHR is not used for care documentation.	Personal Data Act applies.

In Table 4, anonymous PHR refers to a case where the user is not expected to authenticate his or her identity based on real user-identity. Stand-alone mobile applications (without server components) belong to this group. Some server-based PHRs also encourage the subject to use a pseudonym instead of his or her real name[1]. Such services are mainly intended for use in self-care independently of healthcare providers.

A PHR which includes user identities can be exploited in the healthcare process, since patients can give healthcare professionals access to the data and the right to supplement it. In addition, the user can approve copies of clinical patient data to be transferred from EHR to PHR. For practical reasons, in most cases the user gives his or her consent to all healthcare professionals participating in the patient's care process, for the sole objective of providing patient care. Use of the PHR by healthcare professionals must be properly logged to ensure that the above conditions are not violated. When PHR-based information is used in the healthcare process e.g. when making care decisions, the appropriate documentation must be added to the EHR system as discussed earlier in this report. Modern EHR systems have functionality enabling the addition of patient-entered PHR data to an EHR under the control of a healthcare professional.

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[1] http://terveyskortti.fi

5. Health Pocket PHR development

This section describes the PHR development and deployment process performed as part of the WoC project. In particular, the project focused on the exploitation of PHR in the care process for heart patients. The use case provided an ideal framework for development due to the high prevalence of the disease group, its major economic impact and previously identified needs for process improvement. At any rate, the functionalities provided by PHRs can also be widely exploited in the context of other diseases. At the beginning of the WoC project the decision was taken to create a service with the potential to support all care processes, as well as independent health maintenance by the patient.

The idea was that the PHR solution should be both owned and provided by the healthcare service providers involved (City of Tampere, Municipality of Lempäälä, Pirkanmaa Hospital District and TAYS Heart Hospital). The approach taken by the use case is therefore based on the tethered PHR model and the service in question is provided to citizens free of charge.

5.1 Operational environment

The use case addressed by the WoC project is illustrated in Figure 3. Patients with acute coronary events, such as myocardial infarction, are treated at the Heart Hospital. Typical treatments include angioplasty and bypass surgery. Upon discharge from the Heart Hospital, a patient is typically advised to book an appointment with a health centre for a control visit. In many cases, the patient spends some days in the hospital ward (e.g. at the Heart Hospital) after treatment. Rehabilitation services are provided by several organisations including hospitals, health centres, third-sector organisations and private companies. This multi-organisational process is not currently managed as a whole, which has led to suboptimal use of resources during the control and rehabilitation phase.
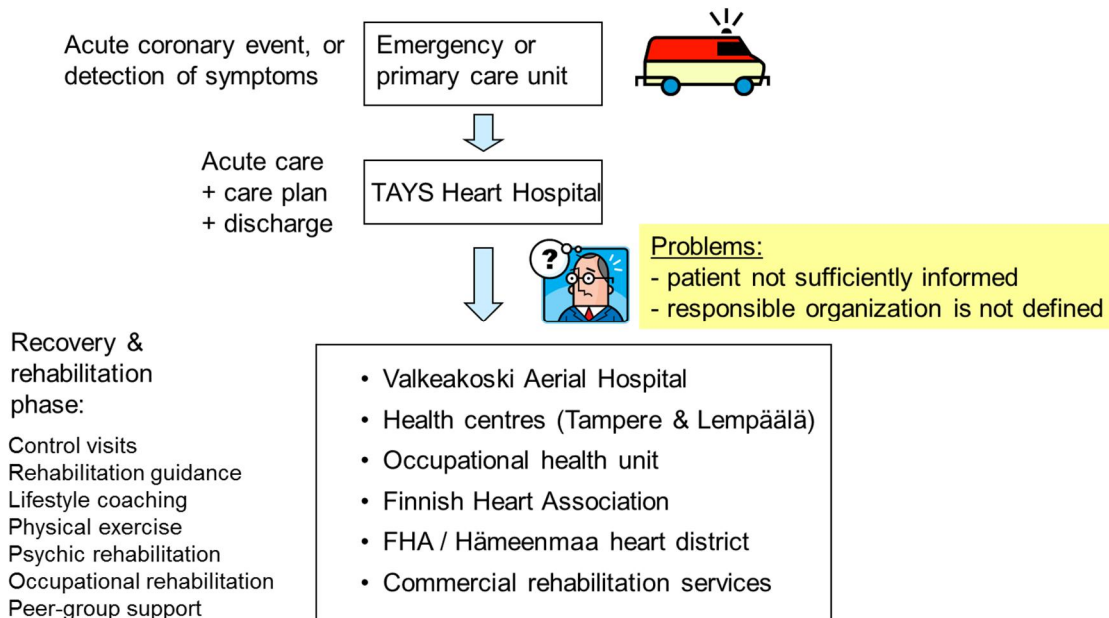
Figure 3. WoC project use case.

5.2   Needs for improvement

The WoC project was a response to a specific need to improve care provided for heart patients; this need was identified by healthcare providers in the Tampere region: the City of Tampere, Municipality of Lempäälä, Pirkanmaa Hospital District, TAYS Heart Hospital, Valkeakoski Regional Hospital, Finnish Heart Association and Hämeenmaa Heart District. Problems with current practices mainly relate to the rehabilitation phase after cardiac events and the related operations:

1. Care delivery is still organisation rather than patient-centric. All patients are treated according to the same (clinical) care guidelines despite their varying personal capabilities, preferences and holistic life situation. Consequently, the care path is not optimised in terms of quality and efficacy of care. For example, many patients are capable for self-care but are not identified, with the consequence that their self-care potential is severely under-utilised.
2. The information flow between organisations contributing to care paths is weak. Primary and specialised care are based on different EHRs, with the result that not all of the necessary patient information is available from the EHR in use and must be requested from the patient.

3. Online services and tools supporting patient self-care are either lacking altogether or inadequate. No use is made of the patient's potential to monitor his or her own health at home. Furthermore, after a care episode the patient has no convenient way of finding information on follow-ups.

It was expected that a PHR would be helpful in overcoming the above challenges. A PHR and the related tools enable the collection of a broad range of information on patients and the use of such information in creating a personalised care path. The patient's notes and other information complementing the EHR data can also be added to the PHR. In particular, a PHR provides the solution required for collecting measurements based on health monitoring performed at home and exploiting them in the care process.

The WoC project used the heart patient care process as a pilot case, with the understanding that similar problems were likely to be found in other care processes. At the beginning of the project it was therefore agreed that the tools to be developed should also be applicable to the care of other diseases. It was also understood that the PHR should be designed as a tool enabling all citizens to maintain and manage their health.

5.3   Development process overview

The main phases of the PHR development process are indicated in Figure 4. The entire process took over five years, which was more than originally planned. Originally, the plan was to implement the PHR via a pre-commercial procurement process, in which case the procurement activity would not need to comply with the Act on Public Contracts[1]. At the start of the project, this plan was changed and the decision was taken to procure the PHR through an open public procurement process in compliance with the Act on Public Contracts. While this meant that the process took more time, the procured solution could be taken directly into full operational use without additional, post-project procurements, which was a considerable advantage. Many publicly funded development activities do not have sustainable results, because the solutions developed cannot be taken directly into operational use.

Additionally, the process was delayed due to efforts to identify a satisfactory solution for PHR-EHR integration. The challenges involved in such integration were partly technical and partly financial, as will be discussed in Section 7.3.

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[1] Act on Public Contracts (348/2007)

Figure 4. Development process phases.

The PHR development process was based on the organisational structure depict-ed in Figure 5. The first part of the activity was carried out by the WoC Task Groups supervised by the WoC project management group. Procurement process tasks were executed by Tampere's procurement unit in cooperation with the WoC Task Group 3. The needs assessment phase was also supported by a series of workshops organised within the framework of VTT's Strada project [46].

The implementation and deployment phases were supervised by the Health Pocket steering group, which included representatives of the procurers, VTT as the technology expert and representatives of the solution provider (Medixine Ltd.). Practical tasks related to implementation and deployment were handled by the Health Pocket project group, which included representatives of each procurer and the solution provider. The PHR development process phases are described in greater detail in the following sections.
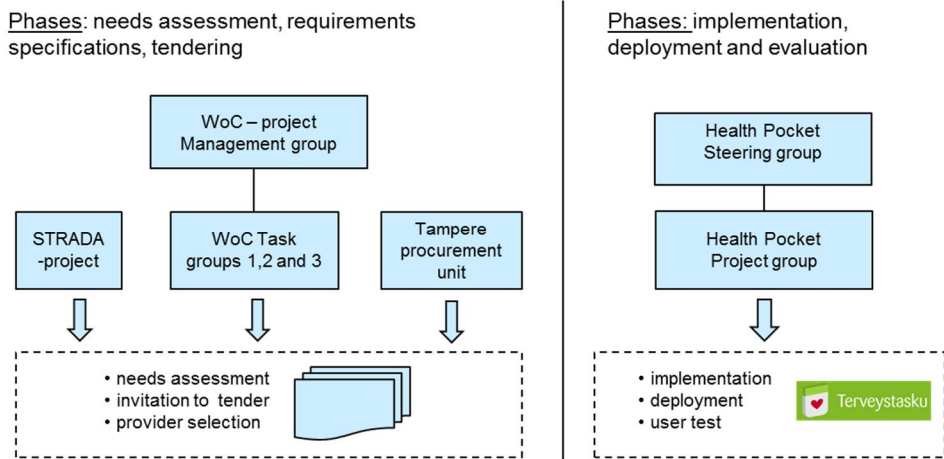
33

Figure 5. Organisational structure of PHR development.

5.4 Needs assessment and concept development

Needs assessment related to the user-centred tools to be developed through the WoC project began in the form of a pre-study prior to the beginning of the project. The pre-study provided background information on the heart patient care process, needs for improving it and the provision of supportive technological solutions [47].

Three technological components were outlined in the pre-study: "Navigator" (decision support and customer segmentation tool), "Health Radar" (tool for finding information on services and events) and "Health Pocket" (the personal health record). The Navigator tool is a questionnaire-based method of assessing the holistic status of the patient, taking account of the patient's clinical condition, social relations and capabilities of using ICT-based tools[1]. Based on the output of Navigator, the patient is guided onto a personalised care path which involves the use of ICT-based tools when relevant, given the condition and capabilities of the patient. Health Radar is one such tool[2]. As such, it is a web-based service which includes useful information on a variety of diseases and health maintenance. It also includes information on other services and forthcoming events. Concept development and the implementation of the three identified tools were incorporated in the project plan attached to the WoC funding proposal. The proposal was submitted in September 2011 and the project began in December 2011.

In order to achieve a deeper understanding of the problem domain, two series of interviews and a customer forum were held at an early stage of the project:

- Interviews with 9 organisations (16 persons) contributing to the heart patient process in the Tampere region. Objective: understanding the current

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[1] http://www.kurkiaura.info/suuntima
[2] http://www.tampere.fi/terveystutka/

- problems and needs of organisations contributing to the heart patient care path (January–February 2011).
- Customer Forum with the participation of 15 heart patients. <u>Objective:</u> understanding the priorities of heart patients during different phases of the disease (April 2011).
- Interviews of 10 authorities with a special insight into the public healthcare delivery system from various perspectives. <u>Objective:</u> understanding the possibilities and obstacles involved in introducing new customer-oriented models for healthcare (November 2011 – January 2012) [41]
- Three workshops (October 2012 – May 2013) [43][44][45]
    - Workshop 1: involving 11 WoC partners. <u>Objective:</u> to develop a shared vision of how customer-oriented services would look by 2030.
    - Workshop 2: involving 21 experts from different organisations and levels (hospitals and primary health care unit, third sector, public administrations, financers, EU parliament, associations, research centres). <u>Objective:</u> workshop aimed at creating a common understanding with the stakeholders deemed necessary for change.
    - Workshop 3: involving 24 experts from the Finnish social and health care sector. <u>Objective:</u> deepening the understanding of what local stakeholders can do to foster change.

Our data collection was conducted between 2011 and 2013 via interviews and workshops. Needs assessment began with interviews of 9 organisations participating in the heart patients' care path in the Tampere region. The focus was on the identification of needs and current problems. The interviews confirmed the existence of many of the problems anticipated in the care process (see Section 5.2).

The need for easy information exchange between organisations was particularly highlighted. More information on the customer's perspective on his or her disease and the management of various treatment phases was provided by the customer forum. The forum revealed the need for patient support, particularly at the time of diagnosis, and, in many cases, for a new direction to be taken in life. In addition to human support, the need for access to all kinds of information on the disease was stressed.

Through these interviews, undertaken to identify the needs of professionals and customers, we discovered more extensive research would be beneficial to achieving WoC's objectives. One of the ideas of WoC was to empower people to manage their own health and medical treatment by providing individual and well-timed support. This should improve health outcomes in a sustainable and cost-effective manner. A change towards attaining the goals of the WoC is not easy, because it involves an ideology that is fundamentally different to the mindset behind the current service system. We require a better understanding of the perspectives of social and healthcare experts on customer-oriented service models and their

adoption into practice. Based on the research questions, we interviewed 10 national and regional welfare and health care experts between the autumn of 2011 and the beginning of 2012 [41].

As a result, the interviewed experts' perceived the need for change towards customer-oriented service models. However, they found it difficult to define what changes would be needed and how they might be implemented. One significant finding was that the entire concept of customer orientation in health care services was considered ambiguous; for many actors, this made customer-oriented service models difficult to grasp. The main obstacles to adopting a new service model lay in lack of resources and the attitudes of professionals and customers. Customers were viewed as the main beneficiaries of the change and the benefits for professionals or society at large were not widely recognised. Change is difficult to promote in a situation where the benefits cannot be identified for all participants. Creating a common understanding of what customer orientation means to the social and health care system, and highlighting the resulting benefits, would therefore be essential [41].

After the interviews, we started cooperation with WoC and VTT's Strada project. The aim of the Strada project was to develop tools to support strategic decision making in complex socio-technical change processes. The WoC project was one of the Strada cases providing an opportunity to develop and try out new tools and methods. Since the interviews revealed that a shared understanding is essential to change, the study was based on an empirical experiment aimed at promoting the creation of a shared understanding of what the change entails and how it can be carried out. The Strada-WoC experiment was carried out with a large network of stakeholders by using participatory foresight, embedding and stakeholder analysis. The aim was to create a platform where different perspectives were heard and discussed in order to promote trust, understanding and a shared vision [42].

The Strada-WoC empirical experiment was divided into three workshops ([43],[44],[45]). In the first workshop, we developed a shared vision with our partners of what customer-oriented services would look like in 2030. In the second workshop, we aimed to create a shared understanding of the stakeholders necessary to effecting change. Based on the interviews and the two workshops, we identified three vision paths representing different levels. The first vision path is about giving more power to customers. The second involves a supporting network and the third focuses on formulating a national definition of policies supporting the change process. These vision paths are not mutually exclusive. On the contrary, all of them are needed in order to promote the change towards customer-oriented service models. It should also be acknowledged that the vision paths are processes in which the participation of multiple stakeholders is necessary. The aim of the third workshop was to deepen the participants' understanding of what local stakeholders can do to foster change.

Change towards customer-oriented services is paradigmatic, as it requires changes in processes, professionals' and customers' responsibilities, attitudes and values, as well as a new division of work between professionals and organisations. As a result of the needs assessment, we acknowledge that the timeline for

the required changes would be long and it requires changes in multiple-levels. In addition to this, the WoC project team realised that in order to foster the change, different levels, organisations and people with different opinions should be acknowledged. Change requires mutual learning, which is precisely what we have promoted in our study.

5.5 Requirements specification

5.5.1 Introduction

The requirements specification work proceeded based on the following steps:

- Identification of the architecture and required interfaces
- Requirements specification of the EHR-PHR interface
- Requirements specification of the PHR

The EHR-PHR interface specifications were recorded separately to the actual PHR specifications. This was necessary because the interface services had to be implemented by the vendor of the existing EHR systems (CGI[1]), while the PHR could be purchased based on an open tendering process.

5.5.2 Architecture

The architecture related to the tools developed under the WoC project is depicted in Figure 6. As shown in the figure, the PHR provides a link between the healthcare professional and customer. The following relevant interfaces were identified for the PHR:

1. **EHR-PHR interface** providing access to EHRs (CGI's Pegasos and Uranus) used in the Tampere region.
2. **Context interface** providing a single, sign-on service and patient context integration with EHR systems
3. **Taltioni interface** providing data exchange with an external interconnected PHR platform (Taltioni[2])
4. **Open interface** to other external services (e.g. the "Navigator" tool)

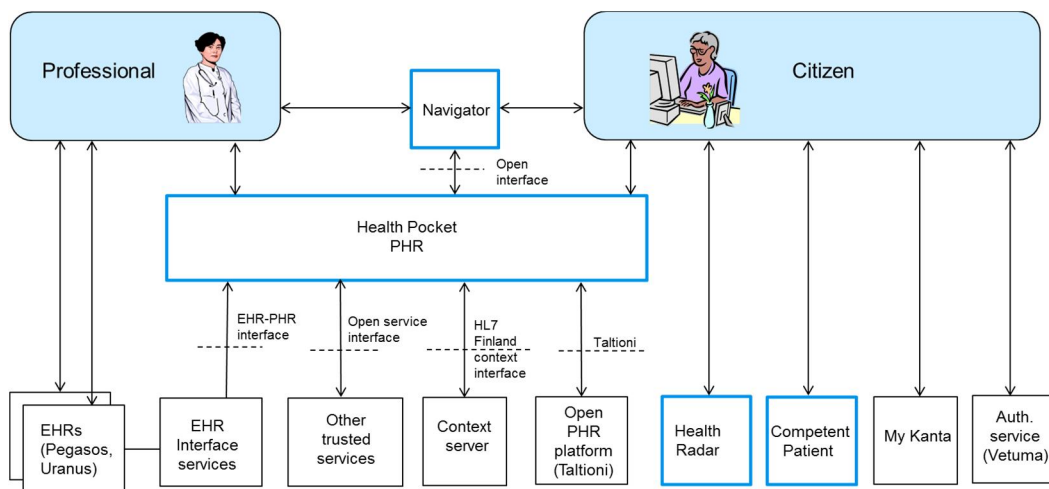[1] http://www.cgi.com/en
[2] www.taltioni.fi

Figure 6. Architecture related to the WoC project. Tools developed in the project are indicated by blue borders.

5.5.3   EHR-PHR interface specifications

As mentioned above, the EHR-PHR interface specifications were recorded separately to the main PHR specifications. The EHR-PHR interface is a service-oriented interface exposed by the EHR. This interface enables the PHR to retrieve clinical patient data from the EHR and display this data for the patient. The objective of writing the specifications was to enable access to the EHR data contained in three systems: two separate Pegasos installations (Tampere and Lempäälä) serving primary care units and the Uranus system used by specialised care units in the Pirkanmaa Hospital District (Figure 6). HL7 CDA R2 was specified as the content standard for the interface. This choice was logical, since CDA R2 is also used by the Finnish national EHR archive (Kanta) and all EHR systems in Finland are under an obligation to implement connectivity with this archive.

During the project, it transpired that the vendor (CGI) was unable to provide a single interface to Pegasos and Uranus. Instead, CGI offered a solution with two, separate interfaces: one for the Pegasos system and one for the Uranus system. The EHR-PHR interface specifications were structured according to the national JHS 173 recommendation[1].

5.5.4   PHR specifications

A set of use cases were defined as a basis for the functional requirements:

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[1] http://www.jhs-suositukset.fi/web/guest/jhs/recommendations/173

1. Customer's login
2. Customer's single sign-on login
3. Main user's login
4. Healthcare professional's single sign-on login
5. Consent and authorisation management
6. Front-page viewing
7. Handling of data transferred from EHR
8. Handling of documents
9. Creating, viewing and management of observations
10. Form filling and submission
11. User management
12. Access rights management
13. Usage report

The above set of use cases covers the essential functionalities of the PHR. Use cases 1–4 address the different types of user login mechanisms. The basic customer login involves user authentication by the Vetuma Service[1], a widely used national online authentication and payment service. Vetuma supports authentication by using network bank passwords, mobile certificates and smartcards. If the customer has already been authenticated by Vetuma to use other services provided by Tampere, he or she can access the PHR without repeating the authentication (single sign-on). 'Main user login' refers to the users of each organisation involved, who are in charge of operating the system. Such users are provided with password-based access restricted to the domain of the corresponding organisation. Healthcare professionals are entitled to access Health Pocket with a single sign-on after being authenticated by their EHR system. This method is based on the desktop integration standard defined by HL7 Finland in line with the international HL7/CCOW standard[2]. It also allows the transition of the patient context from the EHR to the PHR.

Use case 5 defines the functionality required for the customer to provide consent to healthcare professionals accessing his or her personal data in Health Pocket. Use case 6 defines the functionalities to be made available on the front page. Use cases 7–9 provide a definition of the main functionalities, i.e. handling clinical data, documents, observations and forms. Use cases 11–13 cover administrative actions related to user management, role-based access right management and usage reports.

The use cases were defined based on a series of WoC Task Group 3 sessions attended by healthcare and IT experts representing the participating healthcare service providers. They were documented in the PHR requirement specifications document alongside the functional and non-functional requirements. Functional

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[1] http://www.suomi.fi/suomifi/tyohuone/yhteiset_palvelut/verkkotunnistaminen_ja_maksaminen_vetuma/tekninen_rajapinta/Vetuma_v_3_4_tekninen_rajapinta/22_Vetuma_palvelun_kutsurajapinnan_maarittely_v_3_4_eng/Vetuma-palvelun_kutsurajapinnan_mrittely_v_3_4_en.pdf
[2] http://www.hl7.fi/hl7-rajapintakartta/minimikontekstinhallinnan-maarittely/

requirements included overall guidelines for user interfaces and usability and the supplementary specifications of service components introduced in the use cases. Non-functional requirements addressed the interfaces of the PHR in particular, as depicted in Figure 6. Generic requirements for security were also included and the decision was taken to provide the PHR solution on the basis of the Software as a Service (SaaS) model.

In addition to the requirements specifications document, a requirements table was drawn up based on the template and format used by the City of Tampere. The requirements table was divided into three parts: functional, technical and security-related. Furthermore, the requirements were classified into "mandatory" and "important" requirements. The expression of detailed requirements in table form facilitated a fine-grained assessment of each tender and their comparison with other tenders. Compliance with the mandatory requirements was a precondition for all the tenders. The fulfilment of "Important requirements" was used as a comparison criterion when ranking the tenders.

5.6 Tendering process

The tendering process was carried out in accordance with the normal "Open procedure" defined in the Act on Public Contracts. The process was begun in March 2013 with a Request for Information being sent out to potential bidders through the national HILMA[1] online service. The objective was to obtain comments on the PHR specifications and information on existing products and ideas. Responses were received from 10 companies. Each company was invited to a meeting to present the related products and ideas and discuss issues related to the procurement. After these meetings, the requirements specifications were refined in line with the companies' comments and needs for clarification. The Invitation To Tender (ITT) was published in HILMA in December 2013 and the deadline for tenders was the end of January 2014.

As defined in the ITT, the criteria for ranking tenders were based on quality (30%) and price (70%). Quality was assessed based on fulfilment of the non-mandatory ("Important") specifications. Price was assessed based on the fixed deployment project costs and monthly costs calculated for a period of four years. The ranking also took account of the costs of optional functionalities as well as the hourly cost of extra work. Interfaces with EHR systems, the Taltioni interface and the open interface depicted in Figure 6 were defined as options in the ITT. Seven tenders were received for the ITT. The contract was awarded to Medixine Ltd[2], whose solution was based on its existing eClinic product, which supports self-care and interaction between patients and care personnel.

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[1] http://www.hankintailmoitukset.fi/fi/
[2] http://www.medixine.fi/

5.7 Implementation and deployment

The implementation project began in early May 2014, after the signing of the agreement between Medixine Ltd. and the procurers and was executed by the Health Pocket project group, under the supervision of the Health Pocket steering group. The first phase of the implementation project was completed by the end of November 2014 after the successful completion of the acceptance tests by the procurers. The original plan was to complete the first phase two months earlier. However, the delay was not due to the solution provider but to practical difficulties, such as establishing the connections required for providing a single-sign-on service for professional users and Vetuma authentication for customer users. Front page and samples of dialogs and graphs of the Health Pocket PHR are shown in Figure 7.
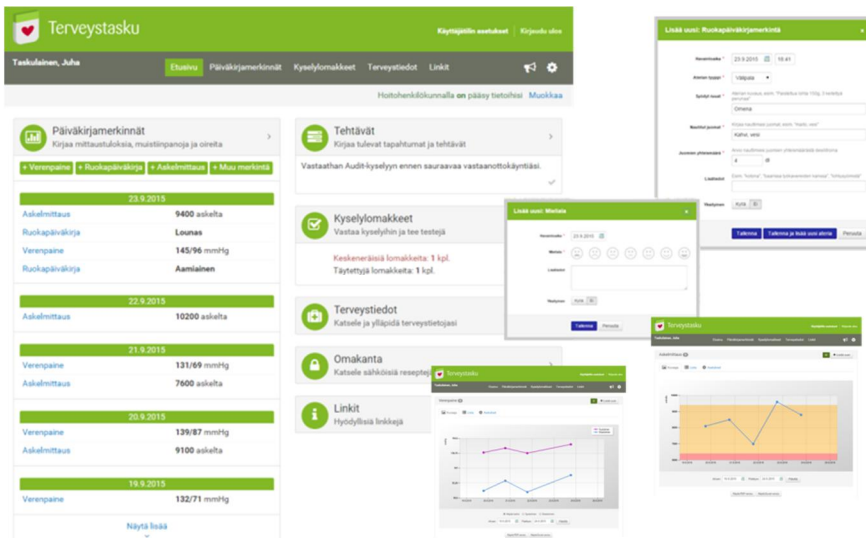

Figure 7. Front page and samples of dialogs and graphs of Health Pocket.

During the course of the WoC project, several workshops were held with the objective of familiarising healthcare professionals in the Tampere region with the concepts of Navigator, Health Radar, Competent Patient and Health Pocket. In these workshops the health professionals also had the opportunity to express their expectations concerning the tools being developed. During the implementation phase, further sessions were organised for the provision of more detailed guidance for professional users of Health Pocket during the care process. During piloting (1.12.2014–31.3.2015), only invited patients were allowed to create a Health Pocket account. The pilot patients were recruited during appointments at a health centre or hospital, upon which they were briefly informed about the functionalities of Health Pocket. Pilot setting is described in more detail in Section 6. Health

Pocket was opened up for the use of all inhabitants of Tampere and Lempäälä on the 1st of April 2015.

Considerable efforts, coordinated by the City of Tampere, were made to publicise Health Pocket among citizens and healthcare professionals. Methods of doing so included billboard advertising, electronic bulletin boards at health centres and promotional materials (videos[1], leaflets). Several promotional campaigns were held in shopping centres, health centres and hospitals.

The security and privacy of the Terveystasku service were audited by an external auditor[2]. The audit revealed several issues requiring attention. In particular, the terms of use required clarification in order to render them clear and understandable to users. Despite being considered valid, some of the audit report's observations could not be implemented for practical reasons. For example, there was no practical way of ascertaining the professional user's patient care relationships, even though such an approach was recommended by the audit. Instead, inappropriate use of data is prevented by systematic oversight of PHR accesses based on reliable log information. The same approach is used in most EHR systems.

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[1] https://www.youtube.com/watch?v=71yuCOKZWc8
[2] Terveystasku-palvelun auditointi – loppuraportti, Pekka Ruotsalainen

6. Health Pocket evaluation

Piloting of the Health Pocket PHR involved patients at the Tampere and Lempäälä health centres, Hatanpää hospital, Valkeakoski hospital and TAYS Heart Hospital. The ensuing evaluation of Health Pocket is described in this chapter.

6.1 Materials and methods

6.1.1 Aim of the evaluation

The aim of the evaluation was to study the use and behavioural intention to use, as well as collecting user experiences (perceived ease of use, perceived usefulness) related to the Health Pocket PHR, in order to evaluate the service for further development. The related research questions are as follows:

RQ 1.   To what extent (use rate) was the Health Pocket PHR used?
RQ 2.   What was the perceived ease of use of the Health Pocket PHR?
RQ 3.   What was the perceived usefulness of the Health Pocket PHR?

Use
Use is defined in this study as the number of signings in per account.

Behavioural intention to use
Behavioural intention to use is here defined as the person's perceived likelihood of using or willingness to use the service or application in the future.

User experience
User experience[1] comprises the "person's perceptions and responses resulting from the use and/or anticipated use of a product, system or service". It "includes all the users' emotions, beliefs, preferences, perceptions, physical and psychological responses, behaviours and accomplishments that occur before, during and after use." It "is a consequence of brand image, presentation, functionality, system performance, interactive behaviour and assistive capabilities of the interactive system, the user's internal and physical state resulting from prior experiences,

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[1] ISO 9241-11: Ergonomics of human system interaction – Part 11: Guidance on usability

attitudes, skills and personality, and the context of use." "Usability criteria can be used to assess aspects of user experience." In this report, we explore the user experience in terms of perceived ease of use and perceived usefulness.

Perceived ease of use is defined as "the degree to which a person believes that using a particular system would be free of effort" [49]. Another, closely related term is usability, which refers to "the extent to which a product (e.g., device, service, and environment) can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use"[1]. Usability is more objectively measurable in some respects, whereas perceived ease of use is a highly subjective form of experience of use.

Perceived usefulness is defined as "the degree to which a person believes that using a particular system would enhance his or her job performance" [49]. In this case, however, usefulness must be considered from the health perspective, with consideration being given to whether use will enhance health and health care.

No system can fulfil its purpose unless it is used. It is therefore important to measure the use of a system and factors affecting its use. Perceived usefulness in particular has been proven to be an important predictor of the intention to use a specific system [50][51]. According to the Technology Acceptance Model (TAM), perceived ease of use and behavioural intention to use affect actual system use either directly or indirectly [49] (Figure 8).
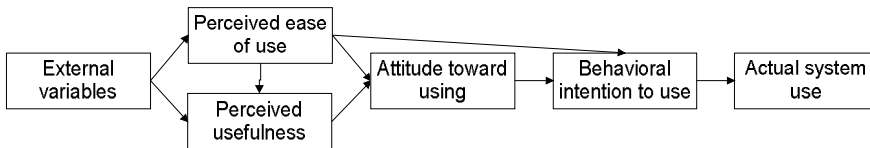

Figure 8. Technology Acceptance Model [51].

6.1.2 Research approach

The research approach should be chosen to fit the research questions/hypothesis being considered [52]. Our research questions are descriptive, describing the use of the Health Pocket PHR and the associated user experience, and can mainly be answered by quantitative means. We employ mixed methods research involving the exploitation of both quantitative and qualitative data collected through multiple methods [53]. Data is collected by using surveys and from server logs. In addition to quantitative data, the questionnaires provided qualitative data based on open-ended questions, with the aim of elaborating on our understanding of the usability and usefulness aspects.

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[1] ISO 9241-11: Ergonomics of human system interaction – Part 11: Guidance on usability

6.1.3 Measures and instruments

The following describes the instruments used to measure the parameters of interest in this article:

- *Use* in terms of the number of accounts and sign-ins was measured, using log files, separately for patients and professionals.
- *User experience* was measured using questionnaires on perceived ease of use and perceived usefulness
- *Intention to use* was measured using a questionnaire item 'Willingness to use Health Pocket PHR in the future' with a scale of 1 'will definitely use' to 4 'definitely won't use', with 5 being 'undecided'.

The following questionnaires were formulated for the purposes of the study:

- Patient questionnaire with 31 items including 28 questions/statements, with multiple answer options and 3 open questions.
- Professional questionnaire with 30 items, including 27 questions/statements with multiple answers and 3 open questions.

6.1.4 Data collection and timeline of the evaluation

The timeline for the launch of the Health Pocket PHR and associated data collection is presented in Figure 9. The Health Pocket PHR was launched on 1st of December 2014 when recruitment for the study began in health centres and the Heart Hospital. Patients were invited to participate until the 31st of March. Since then, the service has been opened up and actively marketed to all citizens in the Tampere region. The service was also opened up to professionals on 1st of December 2014, when they were invited to begin using it. Since the beginning of December, professionals in health centres have been able to access Health Pocket with a single sign-on via the EHR system, without needing to sign-in separately to Health Pocket. During the pilot, single sign-in was unavailable for professional users of the TAYS Heart Hospital, but will be available later in 2015.
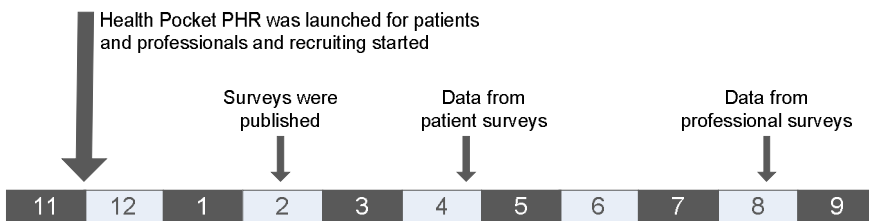

Figure 9. Timeline of the evaluation.

Patients were allowed to use the Health Pocket PHR as and whenever they wished. Additionally, healthcare professionals made suggestions concerning the

use of Health Pocket. For example, persons with high blood pressure were instructed to measure their blood pressure and record the values in the Health Pocket PHR. Professionals at all institutes except the TAYS Heart Hospital were able to access data patients stored in their Health Pocket PHR, via the patient's medical records.

The surveys were published on the 18th of February 2015, around 2.5 months after the launch of the service. The patients were invited to participate in the survey via letters sent after the publication date. Although these letters instructed the recipient to use the link in the Health Pocket PHR, a paper version of the survey was provided with a postage-paid return envelope. This was done in order to gather responses from users who, due to difficulties in using online services, might not have responded to the electronic questionnaire. The last patient survey response was received on 23rd of April.

Professionals received the questionnaires via email after the publication of the survey in February. Due to a low response rate, they were sent a reminder on August 2015, asking them to respond to the survey. The last professional survey response was received on 19th of August.

6.1.4.1   Deviations in data collection

To lower the threshold for replying to the questionnaire, we accepted partially completed submissions. This approach was deemed appropriate because there was no way of ensuring that the paper version of the questionnaire was complete. In some cases, therefore, the responses included missing answers. In a few cases, the number of selections deviated from the requested number, but the effect of this inaccuracy was deemed insignificant to the end result. Six respondents answered some of the user-experience related questions, although they also replied that they had not been using the Health Pocket PHR. We would speculate that, in such cases, the patient had not used the service independently, but together with a nurse, and we therefore included these responses in the analysis.

6.1.5   Data analysis

For the *quantitative* data, basic statistical measures (e.g. the average and standard deviation) were calculated. A content analysis was performed with respect to *qualitative* data provided in response to the open-ended questions. Issues which arose concerning usability and usefulness were categorised under common themes.

6.2 Results

6.2.1 Patients

6.2.1.1 Demographics

Data was received from 52 patients (17 females and 35 males). The average age of respondents was 67 years (SD=10). 27 patients were customers of the TAYS Heart Hospital, 24 of Tampere health centres, 16 of Hatanpää hospital, 14 of the Lempäälä health centres, 6 of Valkeakoski hospital and 10 of other institutions (3 of Omapihlaja, 3 of Acuta, 3 of TAYS, 1 of Tesoma health centre and 1 of Occupational health care) (Figure 10).
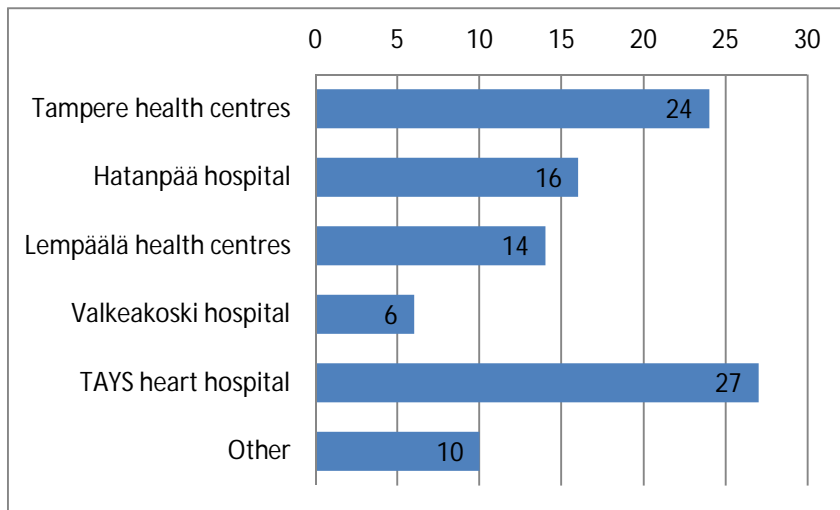

Figure 10. Patients as customers of various hospitals and health centres.

6.2.1.2 Questionnaire statistics

The response time for the electronically answered patient questionnaires varied between 3min 54s and 1h 9min 18s. Once the outliers are removed, i.e. the two longest response times (which were over 45 minutes), the average response time was 9min 56s (SD=4min 57s). The response rate was 67%.

6.2.1.3 Use

According to the Health Pocket PHR log, a total of 78 patient user accounts had been created by 31st of March (number of participants in the study) and 458 ac-

counts by 19th of August. On average, patients had signed into the Health Pocket PHR 7 times per user by 31st of March and 2 times per user by 19th of August.

The survey reveals a great deal of variance in the use period. Most (82%) had used the Health Pocket PHR for less than 3 months (Figure 11). Half (51%) of the survey respondents had signed into the Health Pocket PHR from 1 to 5 times during the study period (Figure 12).
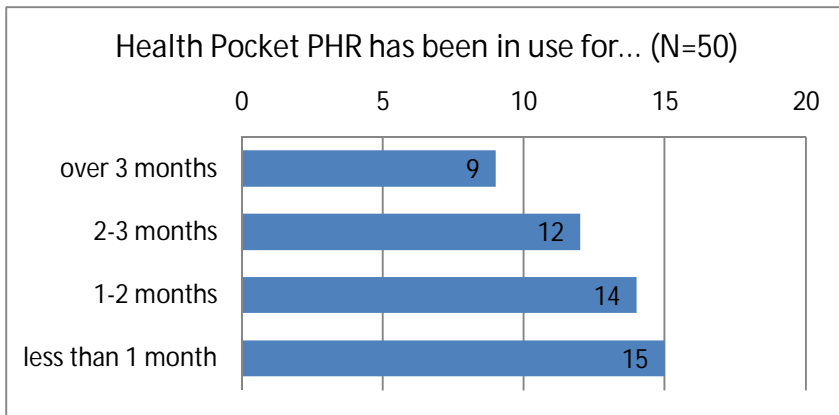

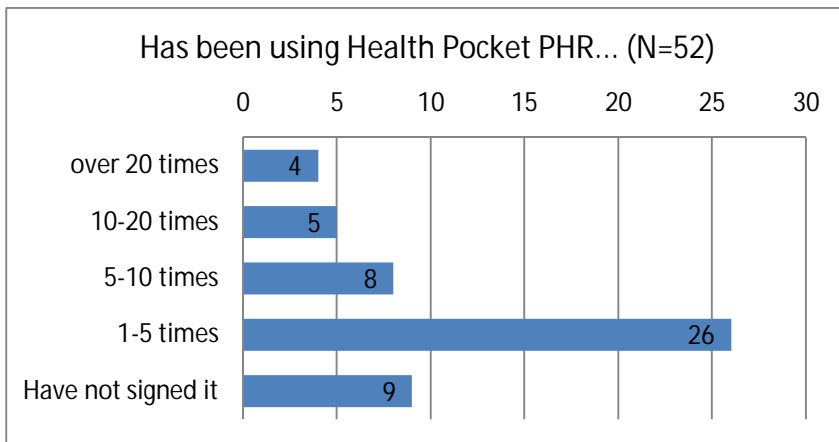Figure 11. Health Pocket PHR in patient use.

Figure 12. Health Pocket PHR sign-ins.

6.2.1.4   User experiences

Results related to perceived ease of use are presented in Figure 13. The Health Pocket PHR was rated easy to use by most (81%) of the respondents. Signing in

was rated easy by most (76%) of the respondents, although some (6/53) reported problems in doing so.
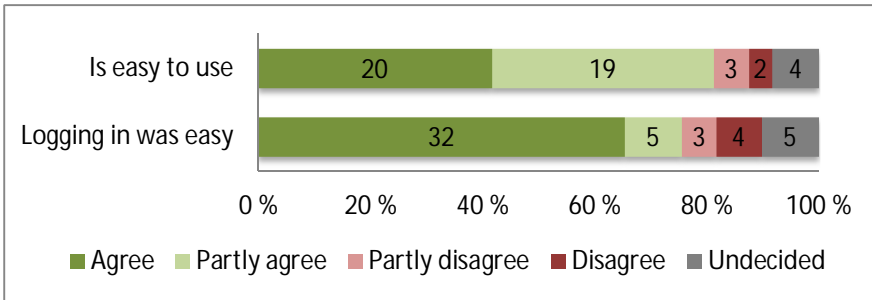

Figure 13. Patient's perceived ease of use of Health Pocket.

Despite the positive response shown in Figure 13, various usability problems were encountered by the patients and reported through open feedback. The results of this are presented in Table 5. The most common comment was related to sign-in problems (6/53). One particularly active patient reported usability issues. Apart from the sign-in problem, the problems encountered and reported were more or less individual issues. Some of these were due to bugs which were fixed directly after being reported.

Table 5. Summary of usability issues reported by patients.

Topic	Usability issue	Needed improvement / remarks
Signing in	Impossible or difficult to sign in (e.g. browser's safety options prevented sign in).	Ensure browser compatibility and take account of variable browser (security) parameter settings.
Graphs and data presentation	Graphs are difficult to follow due to dynamic adjustment of axis scale. For example, the y-axis ticks for blood pressure may contain decimal numbers, which is not appropriate.	The axis should be scaled in an appropriate way for each measurement quantity and should be kept constant for a given quantity whenever possible.
	The default monitoring interval of the physical measurement graphs is too short.	Measurements should have a default time span of over a month.
	Notes made each day are shown separately.	Saved data/notes should be grouped according to the related topic, e.g. sport activities should be gathered under one heading.
	When listing events (e.g. the treatment periods) the chronologically last came first and vice versa, which makes information difficult to find.	Allow user to control the ordering of the task list.
Naming	Naming of user interface items varied ('tasks'/'task list')	
	'Contact person' is a rather strange term for a close relative.	
	Not all of the data labels are self-evident without additional clarification.	Help and guidance should be added to the user interface.
Interaction	Inserting the date for a measurement or task is cumbersome and prone to error.	Allow input of all of the necessary data at once (including date) and include the current time as a default.
	It was difficult to find buttons or links in order to view results, or modify or print data.	Key functions should be visible and easy to access (e.g. modify, print, see results).
	Active and inactive buttons are not distinguishable by colour.	Make clear distinction between active and inactive buttons.
Functionality	A dispensing table for anticoagulant medicine (Marevan) would be useful.	Include dispensing table for anticoagulant medicine.
Information shortage	Official instructions on how to note and measure blood pressure are different from the given instructions.	Include official standard guidelines for physical measurements.

The results for perceived usefulness are presented in Figure 14. The Health Pocket PHR was rated useful by most (88%) of the respondents (3 missing answers).
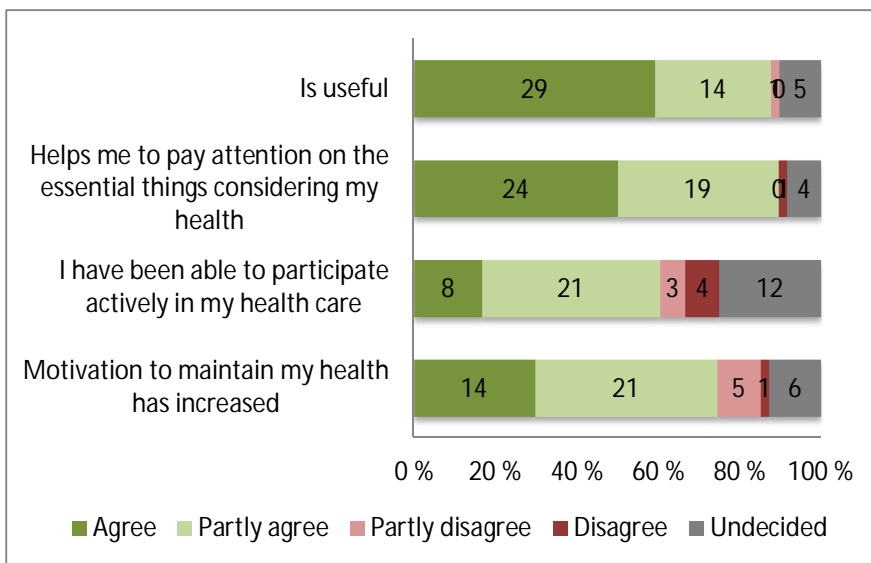

Figure 14. Patient's perceived usefulness of the Health Pocket PHR.

The most useful features were 1) own notes, 2) medication list, 3) pre-appointment questionnaires and 4) document export/search. The most desirable but missing features were 1) viewing one's own medical records (EHR), 2) booking appointments online and 3) communication with healthcare personnel.

Patients commented that value would be added if it were possible to transfer data automatically from other sources (My Kanta, laboratory results etc.). It was also anticipated that more value would be added once professionals became involved and began providing feedback on patients' measurements.

6.2.1.5   Intentions to use

Willingness to use the Health Pocket PHR was recorded in the case of most (94%) of the respondents (4 missing answers) (Figure 15).
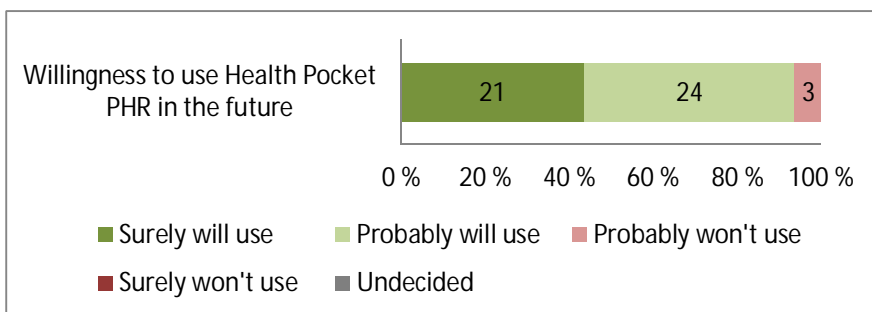
Figure 15. Patients' intention to use Health Pocket.

6.2.2 Healthcare professionals

6.2.2.1 Demographics

This data was received from 17 healthcare professionals (all females), whose average age was 49 years (SD=9). 8 of the respondents were nurses, 3 were public health nurses, 3 were doctors and 3 belonged to other categories of professional (2 diabetes nurses, 1 social worker) (Figure 16). The majority of the professional users (13/17=76%) were therefore nurses. 9 of the professionals were from Lempäälä health centres (main health centre and Kulju), 4 from Tampere health centres (Omapihlaja and Tipotie), 1 from Hatanpää hospital and 3 from other institutions (Linnainmaa health centre, Hervanta health centre, one unknown) (Figure 17).
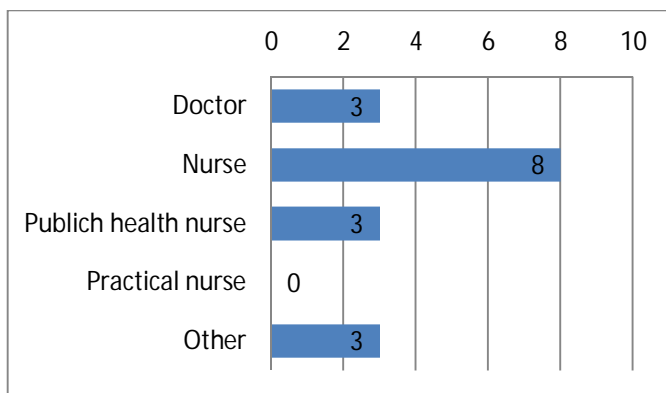

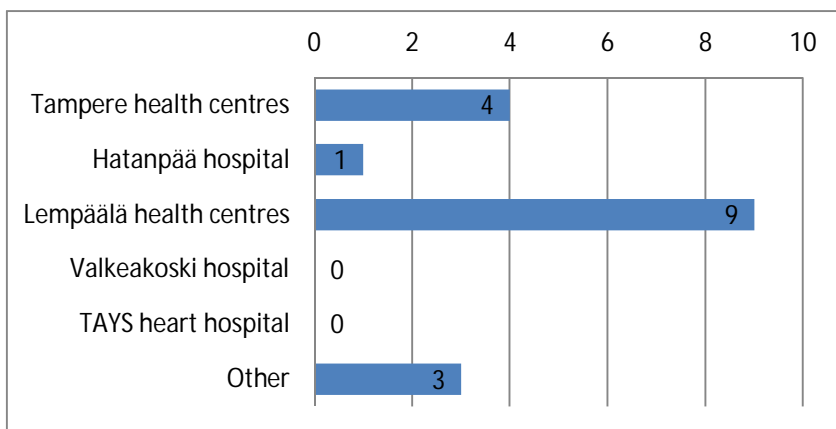Figure 16. Occupations of healthcare professionals.

Figure 17. Organisations of healthcare professionals.

6.2.2.2   Questionnaire statistics

All the questionnaires were completed online. The response time varied between 2min 47s and 2h 28min 39s. When the maximum outliers (those over 45min) are removed, the average response time was 6min 37s (SD=9min 32s). The response rate was 81%.

6.2.2.3   Use

According to the Health Pocket PHR log, 21 professional accounts were created between 1st of December and 19th of August. Professionals signed into Health Pocket PHR 2 times per user on average. Almost half (47%) of the professionals reported that the Health Pocket PHR had been available for use for over 3 months (Figure 18). However, most (76%) had only briefly tested the Health Pocket PHR and had no experience of exploiting it in patient care (Figure 19).
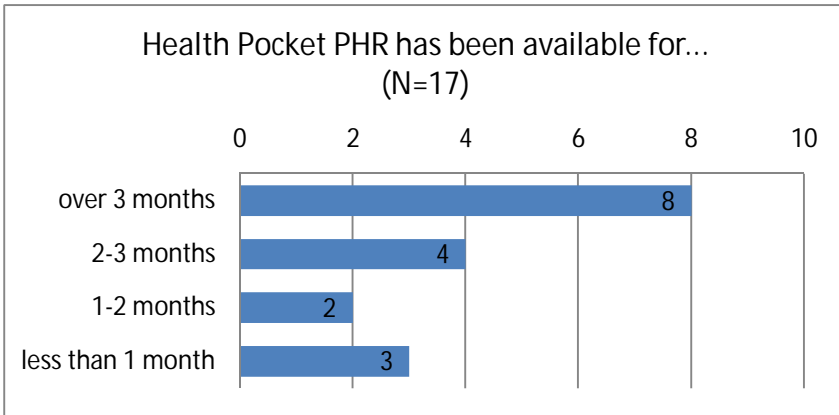
Figure 18. Health Pocket in professional use.
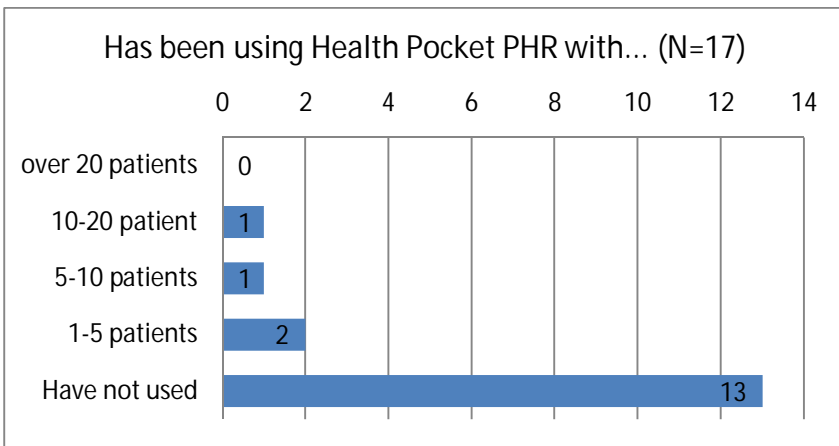
Figure 19. Health Pocket used by healthcare professionals in patient cases.

6.2.2.4   User experiences

The professionals were surveyed about the perceived ease of use of the PHR, the results of which are presented in Figure 20. More than half (59%) of the respondents viewed the Health Pocket PHR as being easy to use. However, it should be noted that a third (35%) of the respondents were indecisive on this issue, reflecting the fact that many of the professional users had only tested the service briefly.

Two of the professionals mentioned that the main obstacle to using Health Pocket is the need to separately sign into another system. These comments reflect the fact that single sign-in via EHR systems was unavailable at the beginning of the pilot.
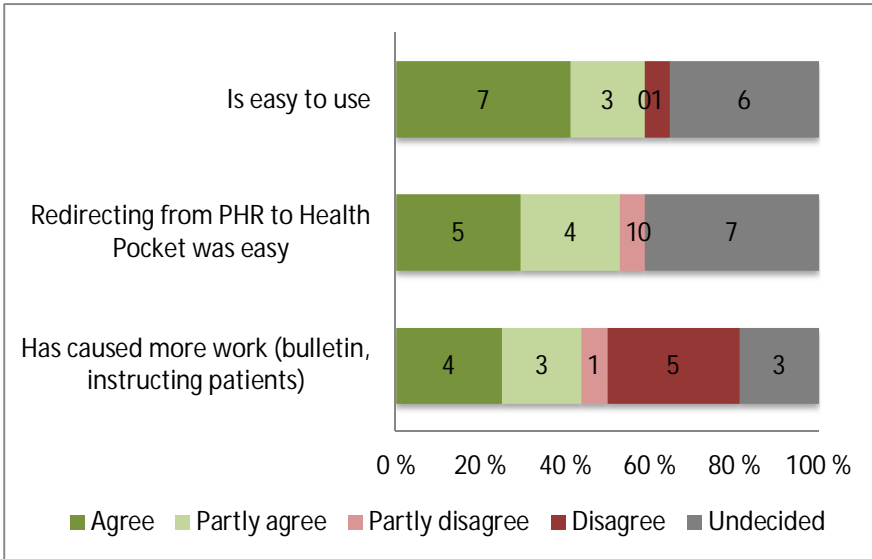
Figure 20. Perceived ease of use of Health Pocket among professionals.

Perceived usefulness among professionals is illustrated in Figure 21. From this, it can be seen that most of the respondents (82%) expect the Health Pocket PHR to become useful when in wider use. Other questions related to usefulness received 'undecided' answers from over half of the respondents, reflecting the fact that many had not used the service with patients.
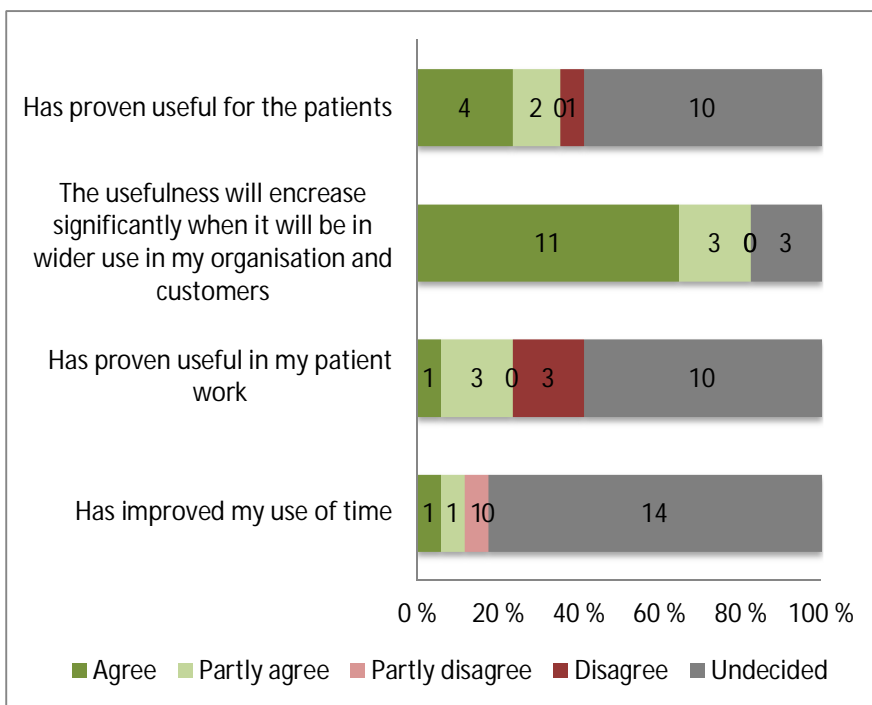
Figure 21. Perceived usefulness of Health Pocket among professionals.

From the point of view of professionals, the most useful features for patients were 1) risk tests, 2) medication list, 3) own notes and 4) pre-appointment question-naires. Of these, features 2 to 4 were also perceived by patients as being useful.

Professionals were surveyed on their perception of what kinds of changes would make the benefits of Health Pocket clearer. The top three issues that pro-fessionals considered to improve usefulness were as follows: 1) improving the compatibility of information systems (11/17), 2) better informing of customers and professionals in order to enlarge the user community (9/17) and 3) changes in care process (6/17).

6.2.2.5   Intentions to use

The intention among professionals to use the Health Pocket PHR is illustrated in Figure 22. Most (82%) professionals were willing to use the Health Pocket PHR at some time in the future.
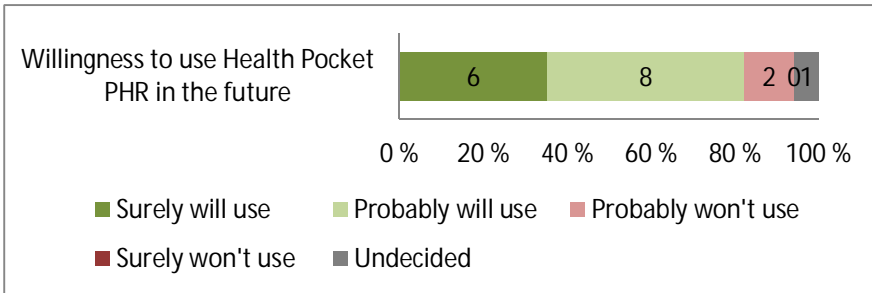
Figure 22. Intention among professionals to use Health Pocket.

6.2.3 Ideas for further development

Some development ideas were received from the patients (Table 6). Integration with My Kanta PHR[1] (Finnish national PHR) was a recurring topic, suggested by 3 patients. A link enabling easy transition to My Kanta was considered important. Although this already exists, it was apparently not sufficiently visible on the user interface. There was also a desire for information transfer from My Kanta to Health Pocket.

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[1] http://kanta.fi

Table 6. Development ideas for Health Pocket by healthcare professionals.

Topic	Wish	Comment
Integration between PHRs and EHRs	Connection between My Kanta PHR and Health Pocket PHR.	Single sign-on (via VETUMA service) is currently available for customer users. This enables the user to move from Health Pocket to My Kanta without a new sign-on. It seems that the actual transfer of data between Kanta and Health Pocket would also be welcomed by users.
	Automatic transfer of laboratory results into Health Pocket.	
Data	Possibility to store a living will.	The My Kanta service already provides the possibility for storing a living will. Not all of the My Kanta services appear to be well known.
	Include a user manual in order to dispel technophobia.	Patient's comment: "I think that written instructions would motivate and encourage users. There must be many people of my age who are afraid to try out computers. By using instructions in the peace and comfort of their own homes they would be better able to find the necessary courage."
Appointment booking	Annual checks notified and booked through Health Pocket.	Patient's comment: "A user of the Health Pocket PHR should receive information on annual check-ups. As it is now, it is impossible to get an appointment as all the nearest slots are booked and the next opportunity only appears after a few weeks – if you are unlucky, only after one month. However, since annual checkups are prescribed by the doctor the date could be set well in advance."
Internationality	National and international (in EU level) coverage of the system (e.g. to support the dispensing of medicine in pharmacies).	

7. Health Pocket use case – discussion

The Health Pocket development process and the user pilot provided practical experiences and insight, which may also be useful in the light of other, similar activities. The main findings are discussed in the following sections.

7.1 Needs assessment

Representatives of several stakeholder organisations were interviewed during the needs assessment phase. The interviews addressed higher-level visions related to the adoption of customer-oriented care models, as well as the practical needs of organisations. Our general observation is that stakeholders agree on the need to change the existing healthcare system and care models. The identified challenges were related, in particular, to the fragmented care delivery system and the inter-faces between organisations, at both the care process and information system levels. A shared vision exists of a need for changes in order to improve co-operation between all organisations participating in the healthcare process.

Stakeholders are also in favour of more customer-oriented care models in principle. However, the concept is not very well-known and views differ on the meaning of "customer-orientation" in practice. For example, the potential to exploit online services as information channels between patients and professionals is not widely recognised. Among healthcare professionals, a PHR is often viewed as a patient activity isolated from the actual healthcare process.

7.2 PHR development process

Public organisations such as municipalities and hospital districts are closely involved in joint development activities, especially those funded through the National Development Programme for Social Welfare and Health Care (Kaste)[1] by the Ministry of Social Affairs and Health. The WoC project differed from the majority of previous development projects in that procurement activities were

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[1] http://www.stm.fi/en/strategies_and_programmes/kaste

carried out jointly by four healthcare providers. Several issues were new to the procurers and needed to be cleared up during the project.

Some of the challenges encountered are described in Table 7. Due to the challenges in question more time was needed for the process, but all of the problems encountered could be solved in the long run. During the requirements specification phase, decision-making was simplified by performing all activities within the framework of the WoC project, which had an approved budget and project plan. At the beginning of the project there was a need for one organisation to take the leading role in the procurement process, in line with the Act on Public Contracts. This role was played by the City of Tampere, which was a natural and beneficial solution due to the key position occupied by primary healthcare in the new customer-centric care model. It was particularly important to agree on how costs would be shared between the procurers, since the objective was to create a service that would exist beyond the lifetime of the project. External funding for the WoC project was available from Tekes, but this only partially covered the related costs (i.e. only those incurred during the WoC project).

Table 7. Challenges related to joint procurement activity.

Challenge	Description
Procurement process management	Management of the joint procurement process was more complicated than normal – for example, decision making was slower.
Leadership of the procurement process	Procurement process execution cannot be shared, but must be handled by a single organisation on behalf of others.
Sharing of costs	Several alternative approaches exist to sharing the costs of a joint service. A decision was required that was acceptable to all partners.
Agreement on functional requirements	Procurers had different preferences relating to PHR functionality due, for example, to their roles as providers of primary or specialised care services.
Agreement on technical requirements	Procurers had different kinds of existing ICT infrastructures, as a result of which they had different needs and readiness for integration.

7.3   Implementation and deployment

From the organisational perspective, the implementation and deployment phase was simpler than the requirements specification phase. After the procurement decision had been made and the service contract signed, a clear plan was available as a basis for proceeding further. At that point, the procurers began leading the process on a much firmer basis and the solution provider was strongly motivated to complete the project on schedule. Delays in deployment were mainly due to integration with the context servers within each organisation, as required for single sign-in to the service by professionals.

During the implementation phase, a decision was expected on the prioritisation of quotation options. These options included interfaces with EHR systems and the Taltioni platform. Additionally, an open interface allowing integration with other applications was included as an option. The Health Pocket steering group decided not to order any of these options for the time being, with the door being left open to ordering one or more options later. EHR system integration would have been particularly expensive due to the changes required to legacy EHR systems, which do not have open interfaces that are directly usable for PHR integration. Instead, as discussed in Section 5.5.3, the required interface functionalities would have to be implemented separately in each of the three EHR systems involved. The high price was also due to a lack of competition caused by the "vendor lock-in effect".

However, costs were not the only reason for omitting EHR system integration. There was also concern among the participating health service providers that the integrated PHR would be interpreted as an extension of the EHR. Uncertainty about the role played by the PHR was highlighted in the Terveystasku audit report[1]. For this reason, professional users were instructed not to store copies of clinical documents for their patients in the PHR. Instead, professional users were encouraged to store care instructions and other less sensitive material in the PHR.

Without EHR integration, the Health Pocket cannot provide customers with access to clinical documents. The responses to the user questionnaire suggest that this decreases its attractiveness. This shortcoming is partly offset by the fact that customers can access clinical data via the national My Kanta[2] service.

7.4   Evaluation

7.4.1   Patient experiences

Most patients had logged into the system only a few times by the time they responded to the survey. For this reason, the survey results are based on a fairly narrow range of practical experience among users. This relatively low level of user activity does not seem to be due to poor user experiences, since perceived usability and perceived usefulness were good and intention to use was therefore pre-

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[1] Terveystasku-palvelun auditointi – loppuraportti, Pekka Ruotsalainen
[2] http://www.kanta.fi/en/3

sumably high. For some patients, however, login problems prevented use of the system at the beginning. Some usability issues were clearly due to the service's incomplete content. For example, not all of the dropdown menus had been properly populated with the appropriate texts.

Patients expressed a desire for the automated collection of data in Health Pocket. Since personal data is already stored in many places – measurement devices, laboratory systems, EHRs and online services – they were of the view that Health Pocket should provide access to such data. This would lower the threshold to using the service and create genuine value for users. Users would like to have seen a better connection with the My Kanta PHR service in particular. In fact, single sign-on from Health Pocket to My Kanta PHR, allowing a relatively smooth transition between the two services, is already available, but most of the patients were unaware of this. After the pilot the link to My Kanta was made more visible in the user interface of Health Pocket.

Professional involvement in the form of commenting on the results would further improve the usefulness of the service and add meaning to stored data. The greater presence of healthcare professionals would also encourage patients to visit the service more frequently. There seems to be a need to help patients from the beginning in tasks such as performing blood pressure measurements and registering results. In addition, Health Pocket so far contains no direct guidance on performing self-measurements.

7.4.2 Healthcare professional experiences

A total of 17 healthcare professionals responded to the survey. Only four of them had genuinely used Health Pocket, while most had only briefly tried it out. This is reflected in the high number of 'undecided' responses to the user experience questions. In addition, only a few answered the open-ended questions – more responses here would have helped us to determine the reasons for the low level of use of the system. Such low activity was partly due to the fact that the professionals did not view the service as being valuable enough prior to its intensive use by patients. It therefore seems that Health Pocket has fallen victim to the classic chicken and egg problem. In addition, the crucial single sign-on feature was not available to professionals at the Heart Hospital, which prevented them from using the service at this stage.

Another reason for low use among professionals may be the high number of systems they use in their work. The threshold for using new services is high even in cases where a direct link and single sign-on from the EHR system are available. It seems that the use of PHR in patient work should be more clearly integrated into the care process and that more guidance is needed for professionals. The requirement for support not only means technical help – according to the comments made so far, healthcare professionals have had difficulties in motivating patients to use Health Pocket. Healthcare professionals also need to learn new ways of interacting with patients in order to facilitate acceptance of the new care model. The study revealed that nurses are the group most interested in using the PHR and the

needs of nurses should therefore be taken into account in the further development of the service.

Although the actual participation of healthcare professionals in the pilot was weak, their responses concerning the potential benefits were mainly positive. There was a strong belief that the service is beneficial once it is in wide use by the organisation. Risk tests were cited as the most useful feature for patients.

7.4.3   Questionnaires and the execution of the study

Data collection based on paper questionnaires is prone to error due to careless form filling. Some questions may be left unanswered by accident, or the wrong format information (e.g. age instead of year of birth) may be given. Using electronic questionnaires, it is also possible to check automatically that all of the necessary fields have been completed and fulfil certain criteria. However, older adults may not feel totally comfortable with computers and providing the option of using a paper form would therefore still be appropriate. In this study, one third of the respondents used the paper version of the questionnaire.

7.4.4   Future steps

The development ideas provided by the patients constituted useful input for further improving the Health Pocket PHR: it is clear that users want to access their personal health data via a single interface. When the project was begun, integration with the local EHR system was planned but was not implemented due to high costs. It currently seems likely that Health Pocket will be more closely integrated with national PHR services that provide access to EHR data. According to the new strategy[1] and development plans of the Ministry of Social Affairs and Health, the My Kanta service will evolve towards open interfaces, allowing the integration of external applications such as Health Pocket.

It is clear that, in addition to technical improvements there is a need to expand the user community among both patients and healthcare professionals. The motivation of patients to use the service will grow if healthcare professionals can view and comment on the measurement data and other inputs stored by patients e.g. in the context of healthcare visits. On the other hand, many healthcare professionals feel that Health Pocket will only become useful when most patients are using it. The Health Pocket implementation plan drawn up by the City of Tampere therefore contains several actions targeted at activating users e.g. by raising awareness through advertising. In particular, during the autumn of 2015 intensive communication and workshops for care personnel will be held highlighting the benefits of the PHR to the care process.

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[1]   https://www.innokyla.fi/web/verkosto463737/uutiset/sote-tieto-hyotykayttoon-strategia-2020-on-julkaistu

8. Conclusions

Customer-centricity and preventive healthcare are commonly set objectives in the reform of healthcare processes. Online services for citizens are important enablers of new preventive and customer-centric care models. This report focuses on personal health records (PHRs) and the related services provided to individuals to enable them to access, manage and share personal health data, either independently or as customers of healthcare services.

Tethered PHRs are implemented by healthcare organisations for their customers. The tethered approach is favourable from the perspective of integrating a PHR into healthcare processes. The interconnected PHR approach is also promising, since it has the potential to enable an ecosystem comprising several organisations using the same PHR service. It is our understanding that both models are viable and can co-exist. The key issue is to make clinical data from EHRs available for customers via PHRs. The key interfaces and related standards for PHR-EHR interoperability have been identified in this report.

PHRs must include personal identity information in order to be connected with healthcare processes and systems. The Personal Data Act provides an essential legal framework for managing such data. Copies of clinical documents can be transferred to a PHR. However, in every case the primary source of clinical documents should be an EHR system in which handling is regulated under healthcare-specific legislation.

The process of developing and implementing a PHR service was studied through the use case provided by the WoC project. Joint development activity enabled the sharing of development and maintenance costs between healthcare providers in the Tampere region. On the other hand, it is evident that some additional overheads and delays were caused by the need to coordinate activities between four organisations. The current trend towards national services is highly attractive – it is evident that the My Kanta service will gradually develop into a national PHR service which allows data generated by citizens to be stored and used in care processes. Local services such as Health Pocket will be needed also in the future, but they must be integrated with the My Kanta services.

The evaluation of Health Pocket was based on questionnaires created for customers and healthcare professionals using the service as pilot users. The number of users remained relatively low throughout the pilot. As a result, the benefits re-

mained fairly limited for both customers and healthcare professionals. Patients hoped that nurses and physicians would examine and comment on their data, while most healthcare professionals considered the service to be one that would be used independently by patients. It is evident that clearer recommendations and guidance are needed on using Health Pocket in the care process. The positive outcome of the pilot was that all users believed that Health Pocket will be beneficial when it is used more widely among patients and healthcare professionals. Patients also had several useful ideas for improving the service and clearly want to access their own patient records through it.

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Appendix A: List of acronyms

ASTM	American Society for Testing and Materials
BG	Blood Glucose
BP	Blood Pressure
CCD	Continuity of Care Document
CCOW	Clinical Context Object Workgroup
CCR	Continuity of Care Record
CDA	Clinical Document Architecture
CHA	Continua Health Alliance
COPD	Chronic Obstructive Pulmonary Disease
EA	Enterprise Architecture
EHR	Electronic Health Record
FEV	Forced Expiratory Volume
FHA	Finnish Heart Association
FHIR	Fast Healthcare Interoperability Resources
HTTP(S)	Hypertext Transfer Protocol (Secure)
ICT	Information and Communication Technology
IF	Interface
IHE	Integrating the Healthcare Enterprise
IT	Information Technology
ITT	Invitation to Tender
JSON	JavaScript Object Notation
MDD	Medical Device Directive
PEF	Peak Expiratory Flow
PHMR	Personal Healthcare Monitoring Report
PHR	Personal Health Record
PHR-S	Personal Health Record System
REST	Representational State Transfer
SaaS	Software as a Service
SD	Standard deviation
SMS	Short Message Service
SSL	Secure Sockets Layer
SOA	Service Oriented Architecture
SOAP	Simple Object Access Protocol
T2D	Type 2 Diabetes
TLS	Transport Layer Security
XDS	Cross-Enterprise Document Sharing
XML	Extensible Markup Language
WoC	Wedge of Cranes project (Kurkiaura project)
WSDL	Web Services Description Language

Title	**Online electronic services for preventive and customer-centric healthcare** Experiences from PHR deployment in the Tampere region, Finland
Author(s)	Jaakko Lähteenmäki, Salla Muuraiskangas & Johanna Leväsluoto
Abstract	Customer-centricity and preventive healthcare are commonly set as objectives when reforming healthcare processes. Online services for citizens are important enablers of new preventive and customer-centric care models. This report focuses on personal health records (PHRs) and related services provided for individuals to help them access, manage and share personal health data either independently or as customers of healthcare services. The objective of the report is to provide useful information for anyone working with PHRs, patient portals and self-care systems – in particular professionals who are responsible for purchasing and implementing such systems. The report introduces the main concepts related to PHRs and highlights their role in disease prevention. It also addresses some related technical aspects, particularly from the interoperability perspective, and highlights the most relevant legislation concerning the implementation and use of PHRs. The study has been carried out within the framework of the Wedge of Cranes (WoC) project, which involved the development of new online tools supporting customer-centric care models. The report describes the PHR procurement and deployment activity performed during the WoC project as a use case demonstrating the PHR development process. Results are given based on the user study completed within the framework of the WoC project.
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