

# Report on the HEC 2016 Workshop: Opportunities and Challenges of Consumer-centric eHealth Services – An Interdisciplinary Workshop

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## 1. INTRODUCTION

With *Horizon 2020* the European Union invests almost €80 billion over 7 years to fund eHealth innovations and services [1]. Germany, for example, is investing about €300 million each year from 2016–2019 in eHealth innovations and the nationwide distribution of eHealth services [2]. Besides funding, a viable eHealth strategy is another important aspect. Already in 2004, the European Commission published the action plan for a European eHealth Area [3]. More than ten years later the countries in the EU have implemented eHealth services at different levels.

In Sweden work has progressed well; the national work involves all care providers according to the National eHealth strategy [4]. In Germany, a new telematics infrastructure (TI) combined with smart electronic health insurance card (eHC) for every insured citizen and a health professional card (HPC) for each healthcare professional was proposed as a national vision to achieve the goal of a more efficient healthcare system. In 2016, the eHC is accessible to citizens, at least in offline mode. However, several regional projects and pilot studies are being conducted [5, 6].

Other countries, such as Austria [7], Luxembourg [8] and Denmark [9] are implementing a national strategy as well, supported by national funding. In Sweden, a national eHealth infrastructure [10] has been implemented which enables health related data to be accessible across care providers, to the patient, and more recently also to researchers via different e-services. Funding is provided both on a national and regional level.

Despite great efforts, differences exist not only for eHealth service adoption, but also on the level of citizen involvement. Given several national strategies based on different technological approaches, border crossers and citizens traveling in other countries will have difficulties sharing their personal health data with physicians in foreign countries. At the same

time, companies such as Apple or Google offer frameworks and related apps to manage personal health information on mobile devices. Today, this consumer-oriented, second health market is mainly driven by wellness, fitness and activity apps. Yet, it is highly dynamic in terms of business models.

Interoperability is crucial for a successful integration of citizen-generated data into primary healthcare market applications. Several interoperability initiatives like *Continua* and *Integrating the Healthcare Enterprise* (IHE) are working on such solutions. The Swedish national eHealth infrastructure proposes an alternative approach in which third party application developers are enabled to connect to the national platform and access data through well-defined and documented public APIs.

The status quo of eHealth/mHealth services in European countries differs in terms of (a) progress (b) heterogeneity and (c) technological and legislative fragmentation. Although initiatives as the infrastructure in Sweden are under implementation, a common international approach is still missing. In this context, a workshop was conducted at the international conference HEC/MIE 2016 in Munich. It aimed to further explore the current state of European eHealth strategies and upcoming challenges for consumer-centric services. In this report, the organizers present the results of the workshop to promote further discussions of this important topic.

## 2. THE WORKSHOP

The workshop was conducted by the German working group on *Consumer Health Informatics*, affiliated with the *gmds*<sup>1</sup> and researchers from *Karolinska Institutet* in Stockholm and *Örebro University* (both in Sweden) who are members of the national *DOMÉ consortium*<sup>2</sup>.

<sup>1</sup>German Association for Medical Informatics, Biometry and Epidemiology, Cologne – [www.gmds.de](http://www.gmds.de)

<sup>2</sup>Deployment of Online Medical records and E-health services

The purpose of the workshop was to analyze current European e- and mHealth trends and to develop pragmatic recommendations towards common European citizen-centric services, compliant with the CHI meta model presented in [11]. Therefore, the primary goals of this workshop can be subsumed as follows:

1. To introduce the participants to the current German and Swedish eHealth status, respectively to share experiences from these two countries,
2. To interactively discuss challenges for developing and implementing eHealth systems for citizens to access their patient information and other eHealth services online from different stakeholders' perspectives,
3. To suggest strategies and actions to resolve some of the identified challenges and to provide insights into different aspects of eHealth services from several countries.

One third of the 90 minutes workshop was used for short presentations in order to stimulate a lively discussion phase among the participants. The organizers defined six stakeholder groups among which the attendees could select one that best suited themselves. At the end of the workshop the results of each stakeholder group were presented in a short summary panel.

## 2.1 Participants

In total, 27 conference attendees participated in the workshop, including: 18 contributors from Europe; 1 from South America; 7 German and Swedish workshop organizers. The organizers served as moderators of the discussion in the aforementioned stakeholder groups.

## 2.2 Short Presentations

After a brief introduction by M. Pobiruchin about the context and the workshop agenda, two presentations on citizen-centred eHealth projects introduced the participants to the status quo in Germany and Sweden.

**Sweden.** The Swedish experiences were presented by M. Häggglund. A virtual patient portal – *1177/Vårdguiden*<sup>3</sup> – is available for everyone in Sweden. Maria presented what the Swedish virtual patient portal looks like, and what personal health information is available to the user after login in to the portal with their BankID. Figure 1 shows the different eHealth services a user can have access to via the *1177* virtual patient portal (here: Maria's own view).

One important eHealth service in the virtual patient portal is the patients' access to their own electronic health record (PAEHR). This service connects, through the national Health Information Exchange platform, to the EHR systems currently in use by different care providers throughout Sweden. In 2012, all patients in Uppsala County were given access to their own EHRs online. Since then, the majority of the Swedish counties have given access, and the services are expected to be available nationally in the near future. Figure 2 gives an overview of the Swedish counties that have currently implemented and provide access to this service (in blue).

Stockholm County Council, one of regions with most inhabitants in Sweden, have begun pilot testing during late

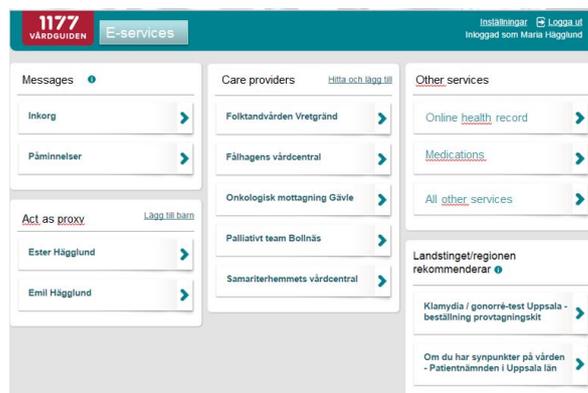


Figure 1: An example of what the virtual patient portal *1177* looks like after valid authentication.

2016 and will implement the service throughout the county during 2017. The goal set in the national eHealth action plan 2013–2018 is that all citizens in Sweden will have online access to their full EHR in 2017. This goal currently looks achievable, however there are important differences in how much information each care provider gives access to, and important regulations are interpreted differently in different counties [12].

When a patient is logged in to *1177/Vårdguiden*, and chooses to access the eHealth service Journalen (the patients online access to their EHR) the user will find the service shown in Figure 3.

In addition to the national Health Information Exchange platform which is used to e.g. give patients access to their EHR, a Health Innovation Platform (HIP) has been developed. The HIP is a part of the infrastructure which is intended to enable third party developers to develop e-health services for citizens and healthcare using APIs that provide access to open data as well as patient data, available at: <http://www.hip.se/>.

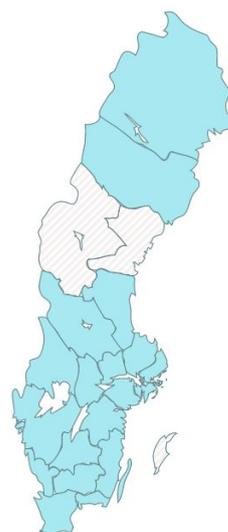
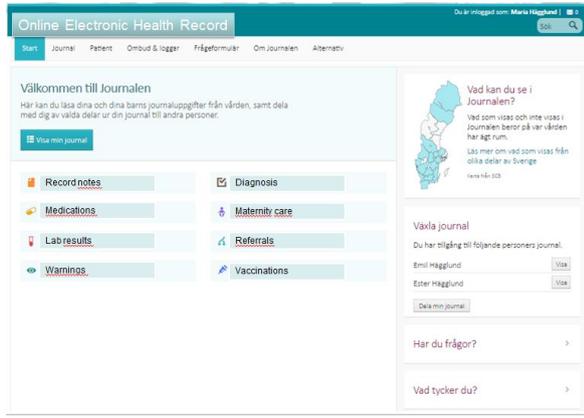


Figure 2: Current implementation of patients online access to their EHR in Sweden, Dec 2016.

– [www.domeprojekt.wordpress.com](http://www.domeprojekt.wordpress.com)

<sup>3</sup>[1177/Vårdguiden](http://1177/Vårdguiden) – [www.1177.se/Uppsala-lan](http://www.1177.se/Uppsala-lan)

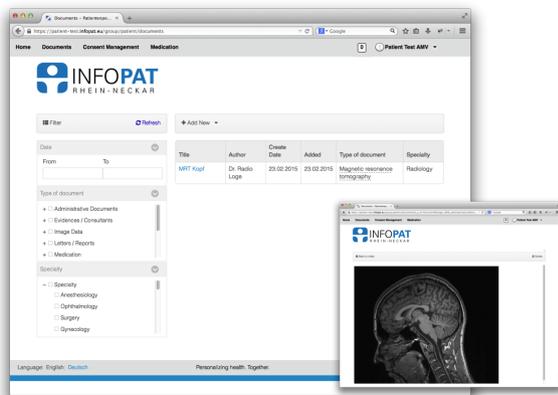


**Figure 3: An example of what the patient’s access to their EHR looks like**

*Germany.* The German experiences were presented by O. Heinze: The German national eHealth strategy is based on a dedicated infrastructure connecting all healthcare providers called telematics infrastructure (TI). The technological backbone is a dedicated, secure network with card-based access for healthcare professionals (HPC), respectively patients (eHC). On top of the TI, secure applications can be built to provide or to support healthcare services like EHR, medication plans or drug safety mechanisms.

In 2016, a new eHealth act [13] strengthens patient involvement and defines a strict time table to roll-out first healthcare services (i.e., medication plan and EHR).

Since the introduction of the TI is delayed for several years, so-called health regions have been established and started projects in a bottom-up approach to build their own standard-based regional EHRs as an infrastructure providing eHealth services to their patients. One example is the personal cross-institutional electronic health record (PEHR, [www.pehr.eu](http://www.pehr.eu)) from the University Hospital Heidelberg in the Metropolitan Region Rhine-Neckar (MRN) which is home of 2.4 million inhabitants. The PEHR is fully controlled by patients in order to manage their health, sharing information among their healthcare practitioners while keeping their informational self-determination, see Figure 4.



**Figure 4: An example of what the patient’s access to their EHR looks like in the INFOPAT project.**

The architecture of the PEHR is based on international, open standards and profiles such as HL7, DICOM or IHE ensuring privacy and security according to German laws. It is vendor independent and scalable from across multiple regions to a national level. The MRN PEHR is used in routine services to exchange documents on a professional level. Several aspects of patient involvement are part of the INFOPAT<sup>4</sup> research project which is funded by the German Federal Ministry of Education and Research. The project runs until 2017 and its results will be translated into routine.

Next steps are (a) to broaden the roll-out and (b) to find sustainable business models and (c) a Spin-off from the University Hospital is working on standard-based architectures and mechanisms to integrate other, third-party mobile solutions such as smartphone apps or smart devices into the PEHR itself. Today, the PEHR implementation in the MRN is already capable to fulfill most requirements, compliant to the new German eHealth law. The approach seems to be adopted by other health regions in Germany as well.

### 3. RESULTS

In the discussion phase workshop participants organized themselves in four stakeholder groups, as listed in Table 1.

Stakeholder group	<i>n</i>
citizens, patients & family members	6
healthcare professionals	5
researchers	2
policy makers & politicians	4
startups & app-developers	–
data privacy officers & CIOs	–

**Table 1: Stakeholder groups and respective number of participants. Note: The 5<sup>th</sup> and 6<sup>th</sup> group could not be established due to lack of participants. Two participants did not join any of the aforementioned groups.**

Each group discussed opportunities of and challenges for consumer-centric eHealth services from their corresponding perspective. Results of the discussions were captured on sticky notes or on a white board by the respective group moderators, as depicted in Figure 5 and 6.

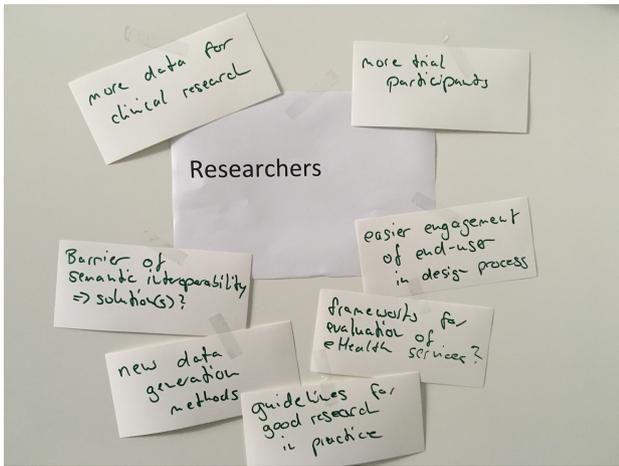
#### 3.1 Citizens

Discussions in the citizen stakeholder group centered on challenges in terms of eHealth services’ use. A summary is presented in Figure 6, as it was documented on the white board during the workshop. Three main themes can be identified for the sub-topics discussed: (a) patient characteristics, (b) eHealth characteristics and (c) relationships.

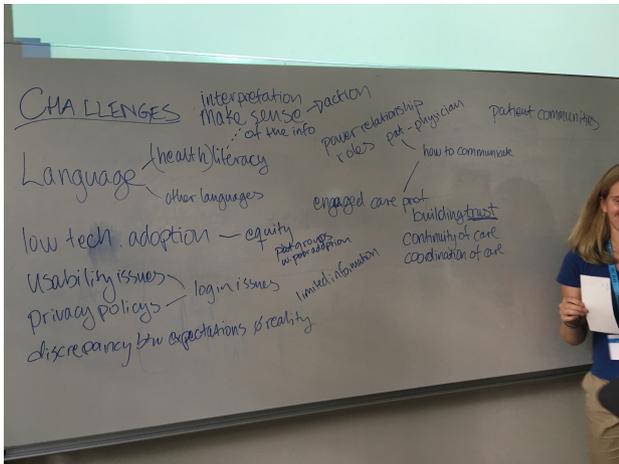
Starting with the patient characteristics, language and health literacy was a given topic. It was identified as an important success factor for the interpretation of available information and the subsequent action a patient may take. In order to take action, patients need certain skills to understand and interpret the information. Technology adoption or digital/computer literacy was also discussed.

Given individuals (maybe whole patient groups) that are not using modern technology and online tools, might result in

<sup>4</sup>INFOPAT: information technology for patient-oriented healthcare – [www.infopat.eu](http://www.infopat.eu)



**Figure 5: Collected sticky notes of the researchers discussion group.**



**Figure 6: Challenges identified in the citizen group**

an increased risk for inequalities in health and healthcare. In particular, this must be taken care of when designing eHealth solutions. Citizens with low technology adoption rate might be disadvantaged if an increasing number of services rely exclusively on electronic devices or access to the Internet. It remains unclear, how these issues can be addressed.

For the characteristics of the eHealth systems, privacy and usability issues might complicate the usage of an eHealth service. This is of course related to issues regarding technology adoption, raising questions (a) who are we designing eHealth for? and (b) how can we improve usability for all? Another important aspect is that there might be a discrepancy between expectations and reality. This applies, e.g., when access is given to information from the patient’s EHR but the information access is limited in certain ways. This can lead to disappointment and discourage citizens & patients to continue to use a service.

Finally, the perhaps most important issue that was discussed dealt with the relationship between patients and healthcare professionals. Communication between professional and patient is key! Engaged and caring professionals are needed to build mutual understanding and trust. How-

ever, within healthcare systems, complex “power relationships” are in place and experience shows that many healthcare professionals are threatened by patients’ access to information or fail to see the benefits of eHealth solutions. In case eHealth services are introduced, roles and relationships between patients and healthcare professionals change. But how can we ensure that this increases trust and facilitates continuity and coordination of care? This was identified as one of the main challenges in the discussion of that stakeholder group.

### 3.2 Healthcare Professionals

The healthcare professional stakeholder group discussed several challenging aspects. The stakeholder group was not limited to physicians only but also included nurses, psycho therapists or pharmacists’ perspectives.

Healthcare systems are complex and there are several heterogeneous ‘data sources’, e.g., machines or patients themselves. As professionals are responsible for the progress of a therapy and its related outcomes, the trust in the data acquisition process is a major concern. This might not be transparent in case health related data is being gathered and analyzed by an algorithm of an eHealth service.

In this context, the participants identified that this particular stakeholder group needs to better understand computational processes, thereby getting a solid opinion on the quality of the acquired data. Therefore, eHealth services should not substitute healthcare professionals but support them in their daily work, e.g., by establishing new ways of communication among professionals and patients or between professionals themselves. Sadly, the additional value of eHealth services is often not directly visible. Moreover, security and privacy issues have been identified as a critical aspect for the trust in digital services.

### 3.3 Researchers

Discussions in the group of researchers (not limited to a certain domain) focused on several expectations arising from eHealth services for consumers. Moreover, barriers for successful implementation of eHealth services were identified. One important expectation, especially from clinical researchers, is the availability of large quantities of data for clinical research through all kinds of new data generation methods. More data raises the expectation for easier and more trial participants. In the creation of new eHealth services researchers hope to be able to engage end-users (e.g. citizens, physicians, etc.) in the design process more easily. Currently, frameworks for evaluating eHealth services are not available. Furthermore, evaluations are not comparable since evaluation criteria differ a lot from each other. Hence, guidelines for good research in practice and technology evaluations seem to be necessary as well. An important barrier which needs to be addressed is the lack of interoperability. Data have to be interpretable across different services and the platforms its service providers. In addition, there is also a need for data exchange between different service platforms in different European countries.

### 3.4 Policy Makers

The major topic in the group of policy makers was focused around how to give *directions* in a very dynamic eHealth/mHealth market in Europe. Different players – such as industry and healthcare professionals – need to be involved

to shape a patient centered ecosystem for modern healthcare systems. The participants discussed different approaches on how to combine applications and services of the mHealth market with the primary healthcare market's structures of providing and billing services. In this context, a key point of that discussion was whether politicians should support a *bottom-up* (BU) or a *top-down* (TD) approach on integrating digital health applications with clinical and home care services:

- BU – Let the market decide what works and is successful for the benefit of citizens and patients.
- TD – Apply regulatory measures by adapting laws to ensure the use of technical standards for the transfer, processing and storage of individuals' data.

### 3.5 Panel – Conflicting Priorities

Subsequently, the aforementioned findings of each group were presented in a short discussion panel. It became apparent that each role has very specific concerns and faces different challenges when using eHealth services.

- Citizens/Patients have high *expectations* related to emerging eHealth applications and services. Yet, they need to be capable to use these in a serviceable manner that meets their individual health literacy level. They also need a functioning partnership with healthcare, rather than current hierarchies and power-imbalance.
- Healthcare Professionals carry *scepticism* related to the quality of data, the validity of the data acquisition process and the trustworthiness of mHealth devices.
- Researchers raise a lot of *questions* related to the comparability of eHealth services, are in need for adequate evaluation frameworks and address concerns on data interoperability.
- Politicians/policy makers need to give *directions* in a very dynamic market. However, it remains unclear whether the appropriate approach should be *top-down* or *bottom-up*.

## 4. CONCLUDING REMARKS

The results of the workshop show that different stakeholder perspectives are essential in the development of *consumer health informatics* (CHI) services. Different challenges and benefits are experienced (or expected) by different stakeholder groups. The discussions during the workshop reflected what is currently described in the literature, e.g., the benefits experienced by patients conflicting or contradicting the skepticism or concerns expressed by healthcare professionals.

The focus on the discussions was mainly on challenges, experienced or expected by the participants. The third aim of the workshop was, moreover, to also propose strategies or activities to address the identified challenges. However, due to the time constraints of the workshop itself, this aim could not be achieved, but the authors would like to propose a few starting points for future research areas that can be addressed by CHI researchers to ensure progression within this important field.

*Merging two worlds of consumer health informatics.* As described in the introduction, eHealth developed with patients or citizens as the main user groups currently exists in

two different worlds: *the healthcare driven applications* and *the personal health driven applications* developed by third party vendors. The first realm includes applications developed by healthcare providers and industry to communicate with patients, increase transparency by e.g. providing access to EHRs and gather data from patients for follow-up or research purposes. In parallel, the personal health market is exploding with self-trackers, etc. that gather unprecedented amounts of data on individuals' personal health. Bridging these two worlds could bring great benefit to both realms. Yet, this requires engagement from CHI researchers as well as healthcare providers and industry.

*Sharing of best practices.* The workshop clearly highlighted that different approaches are taken across Europe and internationally to address these issues, and several countries and regions have reached different levels of maturity when it comes to both technical developments, legal and practical implementation of consumer-centric services. An important area for CHI research in the future is to (a) identify and describe different approaches, (b) share experiences, (c) highlight best practice and success factors, and (d) communicate with industry and healthcare providers and policy makers to ensure the implementation of consumer health informatics in practice.

*Establish CHI evaluation frameworks.* In order to compare progress and results across diverse settings and contexts, and for different types of CHI applications, it is important to have well-defined evaluation frameworks. The authors consider this to also be an important area for future research.

*Involve different stakeholders in the work.* As presented in the workshop discussions, the involved stakeholders have different needs, expectations and experiences in the field of CHI. Therefore, it is imperative to involve all stakeholders in the definition of problems, solutions, and objectives of consumer health informatics to bridge the gap between healthcare and personal health spaces in the future. Patients and/or citizens are outstandingly important to be involved in this work, especially considering the current power-imbalance between patients and healthcare professionals. In this context, it is crucial to develop methods and guidelines supporting developers with the implementation of future CHI services and applications.

As a first step to continue European collaboration within the field of CHI, the workshop organizers have initiated a collaboration with the HOFMI working group<sup>5</sup> in EFMI.

Consumer health informatics will be a new topic within the working group, and we encourage researchers interested in the topic to join the working group to connect, continue the discussion and collaborate on future research.

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<sup>5</sup>[www.efmi.org/workinggroups/hofmi-human-and-organisational-factors-of-medical-informatics](http://www.efmi.org/workinggroups/hofmi-human-and-organisational-factors-of-medical-informatics)

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