

# Chapter 15

## Integrating Patient Consent in e-Health Access Control

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### ABSTRACT

*Many initiatives exist that integrate e-health systems on a large scale. One of the main technical challenges is access control, although several frameworks and solutions, like XACML, are becoming standard practice. Data is no longer shared within one affinity domain but becomes ubiquitous, which results in a loss of control. As patients will be less willing to participate without additional control strategies, patient consents are introduced that allow the patients to determine precise access rules on their medical data. This paper explores the consequences of integrating consent in e-health access control. First, consent requirements are examined, after which an architecture is proposed which incorporates patient consent in the access control service of an e-health system. To validate the proposed concepts, a proof-of-concept implementation is built and evaluated.*

### INTRODUCTION

To date, medical data are shared with a single affinity domain (e.g. hospital, group practice, etc.). Because medical information is very sensitive, its controlled access represents a key security

requirement. This is also reflected by several legislations like the US Health Insurance Portability and Accountability Act and the EU Data Protection Directive. In this respect several frameworks and solutions, like XACML (Moses, 2005), are already standard practice.

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Currently, many initiatives have emerged that aim toward integrating e-health systems on a larger scale. Well-known examples are the Integrating the Healthcare Enterprise consortium (IHE), the UK National Health System, and the European epSOS project. These initiatives aim at creating a unified Electronic Health Record (EHR) containing patient data provided by a wide range of health-care professionals. As scale increases, e.g. when regional or national e-health systems will be fully operational, data will no longer be contained in a single affinity domain and it will become harder for patients to stay in control of how data is used. This results in concerns for the patient who will be less eager to participate in a ubiquitous e-health system.

Moreover, projects like Google Health and Microsoft HealthVault have successfully introduced the idea of the Personal Health Record (PHR) that is a medical file containing health data provided by the patients themselves. Patients are also more and more engaged with online communities (e.g., PatientsLikeMe) where they can provide and share personal health information with peers. We are at the verge of a deeper and tighter integration among different systems (large scale EHR, PHR, communities), which demands for greater and greater control from the user perspective. Once more, it is simply no longer realistic to expect the patient to outsource the control over her own data to care providers (like hospitals) and service provider (like Google) altogether, especially in a converged environment where many stakeholders are involved.

To counter these concerns, electronic patient consents bear the promise of enabling a user-centric access to own medical data and hence re-establish the trust of the patients. Patient consents are user-defined (often complex) rules providing directives on how access to own data should be regulated. Although this is a crucial part of e-health access control systems (as required by compliance to laws and regulations), the related work is rather

limited. Furthermore, the literature is even more inadequate for what concerns the integration of user directives (like patient consents) into the standard practice access control.

As its main contribution, this paper explores the options for representing patient consents and incorporating their directives into the access control decision process. The legal requirements concerning patient consent (with focus on European legislation) are presented first. On top of the results of the legal analysis, we propose a format for representing patient consents and outline the lifecycle governing them, e.g., with respect to their creation and revocation. Finally, we suggest both a policy evaluation algorithm and a reference authorization architecture that incorporates patient consents at its core. The reference architecture extends the XACML authorization model, which is the de facto standard for authorization. In particular, we suggest integrating consents via a Policy Information Point (PIP) interacting with a Policy Decision Point (PDP) that enforces the suggested evaluation algorithm. An implementation of the proposal is presented at the end of the paper, together with an extensive evaluation. As a case study for the evaluation, the prototype implementation is instantiated in the context of XDS, which is an EHR proposal for cross-enterprise data sharing set forward by IHE. XDS is highly promising in the health care sector and is endorsed by key industrial players like Microsoft and IBM, which makes the illustration more relevant.

## **PATIENT CONSENT**

Sharing patient data on a large scale has a big impact on the patient's privacy. Therefore, it is important that the patients themselves are also given the ability to determine rules concerning the access rights of their own data. This section is divided in a conceptual part and a more technical part. The first part provides an introduction to basic

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