

UPCommons

Portal del coneixement obert de la UPC

http://upcommons.upc.edu/e-prints

Xhafa, F., Qassem, T., Moore, P.R. (2014) Collaboration through Patient Data Access and sharing in the cloud. *2014 International Conference on Intelligent Networking and Collaborative Systems: IEEE INCoS 2014: 10–12 September 2014, University of Salerno, Salerno, Italy: proceedings.* [S.I.]: IEEE, 2014. Pp. 205-212 Doi: <u>http://dx.doi.org/10.1109/INCoS.2014.109</u>.

© 2014 IEEE. Es permet l'ús personal d'aquest material. S'ha de demanar permís a l'IEEE per a qualsevol altre ús, incloent la reimpressió/reedició amb fins publicitaris o promocionals, la creació de noves obres col·lectives per a la revenda o redistribució en servidors o llistes o la reutilització de parts d'aquest treball amb drets d'autor en altres treballs.



Xhafa, F., Qassem, T., Moore, P.R. (2014) Collaboration through Patient Data Access and sharing in the cloud. *2014 International Conference on Intelligent Networking and Collaborative Systems: IEEE INCoS 2014: 10–12 September 2014, University of Salerno, Salerno, Italy: proceedings.* [S.I.]: IEEE, 2014. Pp. 205-212 Doi: <u>http://dx.doi.org/10.1109/INCoS.2014.109</u>.

(c) 2014 IEEE. Personal use of this material is permitted. Permission from IEEE must be obtained for all other users, including reprinting/ republishing this material for advertising or promotional purposes, creating new collective works for resale or redistribution to servers or lists, or reuse of any copyrighted components of this work in other works.

Collaboration Through Patient Data Access and Sharing in the Cloud

Fatos Xhafa Technical University of Catalonia C. Jordi Girona,08034 Barcelona, Spain. <u>fatos@lsi.upc.edu</u> Tarik Qassem Warwick Medical School University of Warwick Coventry, UK <u>T.Qassem@warwick.ac.uk</u> Philip Moore School of Information Science and Engineering Lanzhou University Lanzhou, China <u>ptmbcu@gmail.com</u>

Abstract— There have been many socio-political and technological developments in the area of Electronic Patient Records (EPR). The technological aspects include EPR implemented using Online Transaction Processing (OTP) using Internet and Internet based systems, more recently via Cloud-Based systems (CBS) exploiting Cloud Service Models (CSM). Additionally, there are many socio-political considerations comprising: (1) political moves, including UK Government policy, which aims to deliver for patients 27/7 online access to their patient record; (2) considerations around ethical issues and informed permission and acceptance by the public and non-governmental organizations (NGO); (3) technological considerations about identification of suitable CBS and data structures in distributed systems characterized bv unstructured data and, finally (4) sharing and collaboration as means of increasing efficiency, security, privacy, etc. In all, the aim is to provide professionals in medical domain with advanced platforms to not only access but also most importantly to share and collaborate at a wide scale level (e.g. National level). Addressing these aspects of EPR requires collaboration between all stakeholders in EPR; this paper considers these and concludes that such collaboration is essential if EPR are ever to become a reality.

Keywords- electronic patient records; cloud-based systems; cloud service models; NoSQL; sharing; collaboration, sociopolitical issues.

I. INTRODUCTION

There have been many socio-political and technological developments in the area of *Electronic Patient Records* (EPR). The technological aspects include EPR implemented using Online Transaction Processing (OTP) using Internet and Internet based systems implemented using Cloud-Based systems (CBS) with Cloud Service Models (CSM). Additionally, there are many socio-political considerations including: (1) political moves including UK Government policy which aims to deliver for patients 27/7 online access to their patient record, (2) issues around ethical issues including informed permission and acceptance by the public and non-governmental organizations (NGO), and (3) technological considerations including identification of suitable CBS and data structures in distributed systems

characterized by unstructured data. Addressing these aspects of EPR requires collaboration between all stakeholders in EPR; this paper considers these and concludes that such collaboration is essential if EPR are ever to become a reality.

The rapid development in Cloud computing technologies, the availability of Cloud Services Models as well as Cloud Business Models have opened unprecedented opportunities for EPR management. Until the recent past, the EPR were basically used as computerized patient data, usually the amount of data stored were limited, fragmented and mostly locally (e.g. at hospital, care center, etc.) stored enabling mainly individual use. Additionally, most of patient data recorded just basic information on patient through regular / periodic visits. These limitations have had clear negative impacts on the collaboration among professionals of medical teams due to lack of data sharing and limited access in computers hosting data at the hospitals or medical centers. Cloud computing technologies offer services to overcome all such limitations, namely:

- 1. Patient data can be versatile and gathered from different sources. Not only standard Relational Database management Systems but also NOSQL data can be stored and queried for continuous patient monitoring.
- 2. The amount of data to be stored can be practically unlimited.
- 3. Data can be fully distributed and linked across public, private and hybrid or federated clouds.
- 4. Data access and sharing can be provided ubiquitously to any number of geographically distributed users enabling collective use and thus foster collaboration and collective intelligence.
- 5. Security, privacy policies and ethical issues with regard to data usage can be implemented as a service according to different user profiles.
- 6. Auditing policies, such as audit trials, can be implemented to ensure full control on data access and even enabling patients to give their consent on who can access the data.

In this paper we address the above advantages of Cloud computing for EPR management and collaboration and give an outlook on the way they can be implemented in the Cloud.

The rest of the paper is structured as follows. In Section II we give a brief overview of related research addressing EPR is presented followed by consideration of the nature and scope of collaboration required if an effective EPR system is to be developed. An analysis of traditional face-to-face collaboration *vs.* EPR Cloud-based collaboration is presented in Section III. In Section IV we give a few real life illustrative scenarios. Technological solutions to EPR systems that enable medical team collaboration are presented in Section V; advantages, limitations and challenges are also discussed. Section VI discusses security, privacy and ethical issues for EPR systems. The paper concludes in Section VII with closing observations, open research questions, and consideration of future directions for ongoing research.

II. RELATED RESEARCH

Research into EPR systems can be traced back over four decades however the penetration of records, which incorporate more than simply basic information into healthcare organizations is relatively limited. There is a great demand for effective HR systems by all stakeholders in healthcare provision to address a number of issues including (McDonald, 1997): (1) medical record movement and updating problems, (2) realizing improvements in the quality and coherence of care process and to drive process improvement, (3) automation of guidelines and care pathways, and (4) assistance and facilitation of clinical research, outcomes, and management

HR are however very difficult to build as data is generally stored in distributed systems and locations in a diverse range of formats as unstructured data with access and updating using *Online Transaction Processing* (OTP). These challenges are exacerbated because the current electronic data sources which include: hospital systems, laboratory systems, pharmacy systems, and physician dictation systems etc reside on multiple data stores frequently with different structures, levels of granularity, and coding systems (McDonald, 1997).

There is a significant body of documented research addressing EPR, e.g., (Sin, 2008; Calabretto, 2007; Garets & Davis, 2012; Vlug *et al*, 1999; Rogerson, 2000; Balka & Kahnamoui, 2004). The literature contains many studies addressing EPR, see for example the range of related research in the journal of the British Medical Association (BMJ, 2014). However, more recently, the attention of researchers and developers is shifted on using Cloud Computing technologies for EPR management systems; this is an area largely unreported in the literature.

Security of patient data is dealt with by recent approaches as well. Xhafa et al. (2014 a), consider security of patient record data at Cloud using fuzzy keyword search to ensure fine-grained access control. While, in Xhafa et al. (2014 b) attribute-based encryption techniques are used to design cloud-based electronic health record system with attributebased encryption, which guarantees security and privacy of medical data stored in the cloud.

The relative importance of security and privacy has been discussed in the literature; Navarro (2008), Huston (2001), and Bergmann *et al* (2007) are representative examples of studies considering data privacy for patients. As can be seen the research dates back to 2001 and in most cases pre-dates the development of Cloud-based solutions; as for ERP and the Cloud data privacy largely unreported in the literature.

This brief overview demonstrates: (1) the demands that characterise the development of EPR represent a significant challenge, the scale of which must not ne underestimated. The developments in Cloud-Based Solutions merely serves to exacerbate the challenges on both a technological and user acceptance level and the issues that have characterised EPR are equally important in Cloud-Based Systems. Overcoming the challenges demands collaboration between all stakeholders in an EPR system.

III. MEDICAL TEAM COLLABORATION IN THE CLOUD

Team collaboration is a must in medical domain. Many patient cases require discussions and team decision-making. Traditionally, medical team collaboration has been done (and is still done) by face-to-face meetings. With the fast development of Internet-based technologies, Computer-Supported Collaborative Work emerged as a discipline to provide medical teams with Internet-based applications enabling remote collaboration (synchronous or asynchronous) (Koschmann, 2011).

A. Medical team collaborative procedures

In the UK, Patients in the National Health Services (NHS) usually feel surprised know that health professions in hospital environment don't have access to their general practitioners records. They also find it strange when they learn that results of investigations are not readily accessible to different healthcare professionals that are involved in their care. That is particularly true if patients receive care in multiple NHS trusts. As things stand, consultants in acute trusts get a letter or a fax of referral from general practitioners. This letter usually includes a brief summary of the cause for referral, current medical conditions and current medications. It could also include the results of recent investigations. The receiving health professional has no access to any other information. When patient is seen, the hospital consultant may ask for some investigation that could have been already asked for, which could result in duplication of test as well as waste of time and money. Moreover, not all National Health Service trust allow their employers to have access to electronic patients documentation from different places or on mobile devices.

We think that Cloud computing has great potentials in integrating different NHS trusts so healthcare professionals could have access to necessary information needed for patients care. Also, it will help in spreading up the process of referral and communication between primary care and specialist services, through integrating patients' electronic health records. Also, it will dramatically improve efficiency through limiting the need for repeating tests and making health care professional more productive.

Moreover, cloud computing will provide new opportunities for mobile work. In addition to that with the huge computing power cloud computing has, it will provide the chance to use data mining in order to find patterns in services and clinical practice which would help in auditing current services and planning for future development in services.

B. EPR Cloud-based collaboration

Collaboration in relation to EPR) can be viewed on a number of levels: (1) *structural*, (2) *implementation*, and (3) *stakeholder* collaboration.

Structural collaboration relates to the process of creating a computerised EPR system. In such a process there are two important stakeholders: (1) the computer scientist and system developer who will generally have little or no detailed knowledge of the medical conditions and the related outcomes (the *prognosis*), and (2) the medical professional, e.g., the clinician, who will generally have limited knowledge of computerised systems and their development. A significant aspect of future EPR systems is the incorporation of autonomous or semi-autonomous decision support.

Implementation collaboration relates to the processes involved in the actual usage of an EPR system. An EPR system must have the enthusiastic support on the part of healthcare professionals and social services for such a system to be successful. Given this support an effective EPR system can be used to:

- Monitor patients on a day-to-day basis in 'real-time' where medical conditions dictate
- Provide a comprehensive information database on a 'birth-to-death' basis to aid medical treatments in, for example, emergency situations and general healthcare
- Perhaps the most valuable (and far reaching benefit to be derived from and effective EPR system is the ability to analyse data from individual patients and groups of patients. This 'Big Data' approach may enable a predictive capability which may be capable of identifying trends in the data to provide improved projection of prognoses which has potential benefits for patients is terms of *Quality of Life* (QoL), (2) and in the case of Alzheimer type conditions and dementia the carers, more effective use of scarce healthcare resources (both human and facilities), and improved levels of patient care.

Stakeholder collaboration relates to the level to which patients and healthcare professionals accept [and importantly interact with and use] an EPR system. This is vital as healthcare professionals must interact with the system and patient access on a 24/7 basis (albeit less important than acceptance by healthcare professionals) forms an important aspect of EPR systems.

C. Data sharing, annotation and collaboration

Cloud-based EPR systems can support team collaboration in a number of ways. Among them, data sharing and sharable annotation are useful techniques already explored in other application domains (Gertz, 2002). On the one hand, patient treatment may require collaboration of a team of doctors of different specialties; therefore sharing data patient at the Cloud enables timely collaboration. Additionally, members of the medical team can collaboratively build annotation on the patient data. It should be noted that while annotation can be automatically done using meta-data and ontology, in the case of patient data manual annotations from medical experts (doctors, nurses, etc.) is a means to enrich the data. Recently, sharable data annotations are built from crowd sourcing (Hsueh, 2009). While crowd-sourcing solutions come with the challenge of reliability, it is not the case of crowd sourcing for EPR limited to medical experts. Crowdsourcing annotations on EPR can serve as a basis for collective intelligence solutions to support decision-making of medical teams.

D. Constraints to collaboration

Realising effective collaboration as we have briefly discussed involves medical and technical input. Additionally there are ethical, legal, and regulatory constraints. These considerations are discussed in this paper.

IV. REAL LIFE ILLUSTRATIVE SCENARIOS

A. Real-Time Patient Monitoring

Ambulatory monitoring depends on telemetric, which is automatic measurement and transmission of data from remote sources (Princeton University, 2014). These systems use portable, wearable and ubiquitous computed devices, allowing for monitoring behavioural as well as physiological responses of individuals in various situations (Goodwin, Velicer, & Intille, 2008; Intille, 2007).

In 2006, Nusser *et al.* made the assertion that with the technology available at that time it was not uncommon to create a comfortable device that records and transmits a stream of video data of what the person sees, audio data of what is being heard and said, accelerometer data of muscle activities, physiological data such as ECG, GPS information on the subject's location and the feelings of the subject reported to a mobile computer device user interface. With such technology, all of the information collected can be chronologically stamped and synchronised so their relation to time and surrounding is recognised and confirmed (Goodwin et al., 2008; Nusser, Intille, & Maitra, 2006).

For pervasive computing systems to be able to capture data, they would rely on different types of sensors. That range from infrared thermometers, body fat analysers, radiofrequency identification, accelerometers, gyroscopes, and passive infrared sensors. These sensors are either wearable sensors or sensors distributed across the environment. The wearable sensors are usually used for capturing physiological measurements such as heart rate, electricity skin conduction, respiratory rate, or even electrical signals from the surface of the head (EEG). Environment-embedded sensors are usually used for capturing or measuring physical phenomena such as motion, degree of noise or intensity of light. Wearable computing are perception systems that can be embedded into wearable items like jewelry, gloves, clothes or shoes (Wilhelm, Roth, & Sackner, 2003). For example, small unnoticeable on-body wireless sensors have been developed to record respiratory, cardiovascular and muscle activity as well as skin conductivity of freely mobile people(Healey, 2000). Tiny accelerometers and actigraphs monitoring and quantifying physical activities have been embedded into wearable bracelets, wristbands and belts. They can objectively measure dynamic activities (including climbing stairs and walking) and body posturing(Bao & Intille, 2004).

There is now a growing market for consumer wearable sensors which range from wristbands that are able to measure heart rate, calories burned, depth of sleep to newly developed user interface devices that are able to remotely control other computer devices through brain electrical activity. There is merging evidence that commercial EEG headsets are able indeed to detect and differentiate emotions such as excitement or frustration in nonclinical population(Cernea, Kerren, & Ebert, 2011).

Using ubiquitous and wearable computing would be integrated to electronic patient records, so clinicians could have see the changes, over continuous period of time, in certain parameters of interest in relation to medication changes and other medical conditions.

B. Real-Time Patient Monitoring and Big Data Scenario

With the fast development in wireless sensor and mobile technologies, it is possible to monitor patients at hospitals, care-centres and homes. The main challenges behind monitoring solutions are obviously those of big data: volume, velocity, variety, veracity, etc. One can reach easily to gigabytes and terabytes of data if a thousand of patients would be continuously monitored even with a few parameters being measured and stored. This amount would explode if full context information would be catered. In all, the data sensing from patients monitoring produces big data volumes, which should follow a full cycle of data: capturing, gathering, cleaning, transforming, formatting, storing, analyzing, and visualizing. In some case, and depending on patient's state, all this cycle should be covered in real time and data should be available for access by various teams of doctors, carers, nurses, administrative and social agents, etc. (Terzo *et al.*, 2013)

V. COMPUTING PARADIGMS AND TECHNOLOGICAL CONSIDERATIONS

In this section we analyse the maturity of computing paradigms and technological solutions that can serve as basis for Internet-based EPR systems.

A. Ontology and unstructured data

In distributed systems the revolution in the ability to create, store, process, and interact with (including adding to,

removing, and modifying) data creates a paradigm which the traditional RDMS find difficult to manage effectively; the schema-based approach being very restrictive and inflexible. To address this problem unstructured database systems (generally grouped under the term 'NoSQL') have been created.

Recent research (Curé *et al*, 2013) has sought to extend the research into 'NoSQL' database technologies using Ontology Based Data Integration Over Document and Column Family Oriented NoSQL stores. These new data stores are regrouped under the NoSQL label (but coSQL is another recently proposed name). The First successful NoSQL databases were developed by Web companies including the pioneers: Google (with Big Table) and Amazon (with their Dynamo). Currently, 'NoSQL' database systems are used in a diverse range of applications and systems and are present in cloud computing environments. In discussing unstructured data and Internet-based systems Curé *et al* (2013) have observed: "Data can not miss the opportunity to address and integrate technologies and datasets emerging from this ecosystem".

Curé et al (2013) introduce an interesting and potentially useful approach, which in proposing an integration framework where the target schema is represented as a Semantic Web Ontology (SWO) and the sources corresponds to NOSQL databases. The principal issues in integrating a 'NoSQL' database system and a SWO are the lack of a clearly defined schema and declarative query language.

The benefit of an approach, which does not rely of a schema, is flexibility (a feature of 'NoSQL' approaches) in terms of the ability to model data. This however can be an issue where defining relationships between more difficult as in general 'NoSQL' systems require bespoke programming (SQL systems generally use a well developed syntax); thus 'NoSQL' systems are more difficult to build.

Cure et al (2013) propose an approach, which generates a local schema for each integrated source using an inductive approach. This approach uses non-standard description logic (DL) reasoning services such as the Most Specific Concept (MSC) and Least Concept Subsumer (LCS) to generate a concept for a group of similar individuals and to define hierarchies for these concepts. Additionally, Cure et al (2013) claim that their approach provided for the specification of a global ontology based on the local ontologies generated for each data source. This global ontology results from the relationships discovered between concept definitions present in each local ontology.

Concerning the lack of a common declarative query language, Cure et al propose a Bridge Query Language (BQL) which supports the "translation" from the SPARQL query language to different query languages accepted at the data sources. A general feature of 'NoSQL' document and column family database systems is the lack of a declarative query language such as SQL. The approach adopted is (again generally) a procedural approach using, for example, specific Java API's. To address this aspect of the problem Cure et al (2013) propose the BQL approach. For a detailed discussion on this interesting approach see Cure et al (2013).

The relevance of this approach to the topics discussed in this

paper lies in the ability to address the massive concurrency and dynamic loading imposed by OTP with the semantic descriptions that are a feature of healthcare systems. Indeed, as we assume the patient data monitoring is part of the EPR system, there is a need for NoSQL and ontology approaches for at least three reasons: 1) the data come into streams (perhaps in real time) and cannot be made persistent using traditional RDBMS 2) patient data monitoring is mostly used for reading/processing and not for updating/modifying, which justifies to sacrifice ACID properties of RDBMS in order to gain efficiency through schemaless NOSQL databases and finally 3) patient data monitoring is of multiple sources (text, sound, video, etc.) requiring and efficient integration of local ontologies of particular data sources into a global ontology.

B. Cloud-based systems

Having discussed aspects of collaboration and the related medical monitoring we now turn to the cloud-based systems. We consider *Cloud-Based Systems* (CBS) and provide a comparative analysis of the relative merits with of the Cloud types. *Cloud-Service-Models* (CSM) are discussed in view of how such systems can support EPR systems and overcome limitations of existing approaches.

1) Cloud-Based Systems

Cloud-Based Systems (CBS) generally fall into three distinct types: Public Clouds, Private Clouds, and Hybrid Clouds (Moore & Sharma, 2013; Moore et al, 2014). Figure 3 graphically models the three CBS, the relationship that exists between a private and public cloud when used in concert to create a hybrid cloud.



Figure 3: Cloud System Types (source: Moore et al, 2014).

There is generally an element of confusion around the concept of the 'Cloud'; there being no generally agreed definition of the term. In asking: "What is Cloud computing?" Hartig (2008) observes: "the cloud is a virtualisation of resources that maintains itself". This definition, while adequate in a general sense fails to capture the complexities that characterise Cloud-based solutions.

Space restricts a full discussion on the three cloud types; a detailed discussion can be found in (Moore *at al.* 2014)

however in summary the essence of cloud-based systems lies in the relative positive and negative aspects of each cloud type. We set out below a comparative analysis of the cloud types.

C. Comparative Analysis

In considering the Cloud solutions, a comparison between Public and Private Clouds demonstrates that each has positive and negative aspects; a summary is presented in Table 1. The tabular comparison identifies the differing functional properties that characterise *Public* and *Private* clouds. It is however incorrect to refer to positive and negative characteristics; the correct interpretation must be related to the domain of interest. For example in a health domain security of patient data is critical, thus a public cloud is not a practical solution however a public cloud would provide the scalability to address non-critical functions. In such a case a hybrid cloud may be the optimal approach. A brief overview of each characteristic is as discussed below.

While the *initial cost* comparison is clear this may not be the overriding factor in the selection of a cloud solution type. The other factors identified arguably have greater prominence. As with the *initial cost*, the *Running Cost* is domain specific and will be influenced by the capabilities realised based on the remaining factors.

TABLE I. CLOUD TYPES – A COMPARATIVE ANALYSIS

Characteristics	Public Cloud	Private Cloud
Initial Cost	Low	High
Running Cost	Variable	Variable
Customization	No	Yes
Privacy	No	Yes
Security	Problematic	Manageable
Regulation	Problematic	Manageable
Single Sign On	No	Yes
Scalability	Simple	Difficult

Customisation: is central to a user requirements specification. Where customisation forms a central plank in the requirements (as in the case of the healthcare domain) a *Public* Cloud alone is arguably not an optimal option. A *Private* Cloud would offer the facility to tailor the service to suit the domain specific requirements of a hospital domain.

As for *customisation*, a *Public* Cloud fails where *Privacy* is concerned; this is pivotal where *security*, *privacy*, *legal*, and *regulatory* requirements are concerned. A *Private* Cloud may offer the facility (in a hospital setting) to implement the security requirements with clearly defined access rights and permissions based on defined roles (e.g., clinicians, nursing staff, auxiliary and management staff).

Compliance with *regulatory* regimes including: data protection statutes [which are clearly vital in healthcare systems] and implementing security [principally data security] while problematic for a public cloud is manageable for private clouds.

The capability to implement a *single sign on* is, as for other characteristics, domain specific and may be a useful function or alternatively a security risk.

Scalability is crucial in a hospital domain where the dynamic nature of the environment demands scalability both in the immediate demands but also over time. In a public Cloud solution scaling up is relatively easy while within defined limits however in a private Cloud solution scaling up is more laborious and may entail significant infrastructure investment in terms of hardware, software, and human cost; the scope to scale up is however potentially limitless.

This brief overview of CBS identifies the relative benefits attributable to each Cloud classification. In a health service model there is a clear need to provide for high concurrent dynamic *Online Transaction Processing* demand (which points to a public cloud) with data security (which points to a private cloud). Therefore, to obtain the benefits of a public and private cloud the hybrid cloud model (see Fig 3) offers potential benefits.

D. Cloud Service Models

An integral part of CBS is *Cloud-Service-Models* (CSM) (Moore & Sharma, 2013; Moore *et al*, 2014). There are a number of mainstream Cloud Service Models: (1) *Software-as-a-Service* (SaaS), (2) *Platform-as-a-Service* (PaaS), and (3) *Infrastructure-as-a-Service* (IaaS). In addition to the 3 service models identified there is also a service model termed Network-as-a- Service (NaaS). Space restricts a detailed discussion on CSM however a discussion can be found in (ref).

E. NoSQL Database Systems

There have been dramatic changes in Internet and Cloudbased systems in the way users interact with such systems. These developments are driven by a number of challenges:

- The massive increase in the numbers of concurrent interactions using both fixed, wearable, and mobile devices
- The increasing capability to capture, create, interact with, and store data in increasingly diverse formats
- The explosion in the volume of unstructured or semistructured data.

Addressing these challenges using system based on *Relational Database Management Systems* (RDMS) has proved to be a very difficult problem. A significant reason for this difficulty is the architecture of RDMS, which is based on a rigid schema and is (generally) designed to operate on a single computer system. As such RDMS have not proved to be amenable to *Scaling* to accommodate the challenges identified above.

Addressing the limitations [where unstructured data is concerned] of RDMS has been the subject of a significant research effort; pioneers of database systems capable of operating on unstructured date (frequently termed: 'NoSQL') are Google, Amazon, and Facebook whose systems suffered from the issue of unstructured data. Space restricts a detailed discussion on the topic however we have presented a detailed consideration in Moore *et al*, 2014. In summary the use of 'NoSQL' technologies is gaining traction among Internet and commercial organizations where the benefits of *scalability* in a system not constrained by a rigid schema are a functional requirement.

Turning to EPR there are socio-political imperatives driving moves towards the implementation of EPR in Internet based systems with OTP. Such systems can be viewed in terms of Cloud-Based systems; for a detailed discussion on Cloud-based systems see Moore *et al* (2014) where Cloud-based systems and the related Cloud-Service Models are introduced the issues around data security and issues around data privacy and security are considered.

OTP in EPR where there are extremely high concurrent loadings in highly distributed systems has demonstrated the limitations inherent if RDMS as evidenced by systemic failures in attempts to implement EPR in the UK where there are some 50 million patient records (see Moore *et al*, 2014) where the resultant failure is highly instructive.

F. Summative Evaluation

This section has considered the technological considerations implicit in the development of an EPR system. Clearly, there are important constraints as we have identified however addressing the ethical and acceptance issues form a vital aspect of EPR. The computing paradigms and the technological infrastructures together with the widespread of broadband Internet connections have matured to the point of making it feasible to seek satisfactory solutions for Cloud-based EPR systems and for their adoption by national and private health sectors.

VI. SECURITY, PRIVACY, ETHICAL ISSUES AND ACCEPTANCE

This section considers the twin challenges that face healthcare systems, namely: audit trails with ethical and acceptance issues including informed consent.

A. Audit trials for patient data security and privacy

EPR systems are sensitive systems in terms of security, privacy, anonymity and rights access to data. The state of the art using Cloud computing technologies has so far been concerned with such issues but without having into account two issues: 1) access to data is multi-user access and 2) patients have not been taken into account. With regard to the first, the multiple-access to the data by different doctors or teams of doctors is a *must*. For example, a doctor of a patient of dementia should have access also to routinely collected data of the patients for physiological parameters such as blood pressure, temperature, weight, etc. over time. Regarding the second, the question is whether the patient should know who is accessing the data and even to be asked to give consent to who can access his data.

One approach that can satisfactorily address both issues is the audit trial, defined as (see National Information Assurance Glossary, 2014):

An audit trail (also called audit log) is a securityrelevant chronological record, set of records, and/or destination and source of records that provide documentary

evidence of the sequence of activities that have affected at any time a specific operation, procedure, or event.

The difference between applications of audit trials for transaction logs or in other field where are limited to the privacy/security office, with that of EPR is that such audit trial can be also available to patients (or their carers), who can act upon. In fact, the audit trial for EPR can be enriched also with other information such as location access, medium access, etc. to address some location-based security issues. It should be mentioned however that there is a challenge to audit trials for EPR systems. Indeed, assuming EPR data is large and assuming active interaction with the data, the amount of audit log would be too large to be human readable and manageable. This brings us again to the need for a data cycle definition for audit trial for EPR. This is even more challenging if we are to include as part of EPR data, data monitoring of patients, which produces even much larger data (big data).

B. Ethical and acceptance issues

In December 2013, NHS England directed the Health and Social Care Information Centre to establish a system for uploading and linking GP patient coded data with identifiers. However, that plan proved to raise concerns of several professional bodies as well as the public. These concerns were mostly related to privacy, security and selling these data to the commercial sector (Todd, 2014).

The principles for autonomy, beneficence and nonmalfeasance are widely accepted ethical doctrines in health care (Beauchamp & Childress, 2001). In this model, **respect for autonomy** translates into the individual's entitlement to make decisions that are related to their own treatment. In this context, sharing patients, though anonymous, should be after having patients consent, especially as cloud based patients records could significantly affect individual's privacy and entitlement to confidentiality. Meanwhile, the principle of **beneficence** refers to the commitment of healthcare providers to be of benefit to the patient, in addition to taking positive steps to prevent and remove harm from the patient. While, **non-malfeasance** refers to refraining from any act that could lead to patient's harm (Beauchamp & Childress, 2001).

We believe that, though the benefits to patients from such cloud based EPR are many, as with any technology, pervasive computing and the use of Big Data in management of health care needs establishing rigorous safeguards to protect against their possible abuse. As violation to individual's privacy is a real threat, concerns need to be addressed through policies and regulations in addition to robust enforcement.

One cannot argue against using banks although they deal with private data everyday. The same principle should apply to the use of technology for health care purposes. We believe that in spite of the reality of the threat to patient's privacy, denying the use of new technology under privacy concerns would be unethical. We believe that, the data owner, in this case it is the patient, needs to be in control of who has access to his data and where his data goes. In this model, the data owner would have the right to give data access to specific individuals or bodies. At the same time, the data own should have the ability to revoke those privileges, which could pose technological challenge in its self.

VII. DISCUSSION, CONCLUSIONS AND OUTLOOK

In this paper we have analysed the issues arising from the development of advanced EPR (Electronic Patient Records) systems. Such issues have been identified through various dimensions: (1) the need to develop EPR systems that enable collaboration of all involved actors from the medical sector (doctors, nurses, carers and stakeholders); (2) the need to handle much richer patient data in the EPR as compared to traditional EPR systems. Such data should also include data generated during patient monitoring; (3) data security, anonymity and privacy by taking into account multiple access to data and patient rights to be informed on who accesses his data and consent to protect the data access; (4) the maturity of computing paradigms and technological infrastructure to support advanced EPR solutions.

We have provided a model based on Cloud computing that can address the identified issues: (1) collaboration at the Cloud EPR system can be achieved through data access and sharing; (2) patient data monitoring can be stored in Cloud EPR system by using NoSQL and ontology solutions than enable to integrate different data sources and local ontologies into global ontology; (3) data security, privacy and patient consent to data access can be achieved through audit trial implemented as a service in the Cloud EPR system, and, finally, (4) the existing computing paradigm and technological infrastructures are found mature to fully support Cloud-based EPR systems.

ACKNOWLEDGMENT

This research work has been supported by TIN2013-46181-C2-1-R Computational Models and Methods for Massive Structured Data (COMMAS).

REFERENCES

- [1] E. Balka and N. Kahnamoui. (2004). Electronic Patient Records.
- [2] BMJ, Implementation and adoption of nationwide electronic health records in secondary care in England: final qualitative results from prospective national evaluation in "early adopter" hospitals, *BMJ*, 2011;343:d6054 doi: 10.1136/bmj.d6054, 2014.
- [3] J.P. Calabretto. (2007). Supporting medication-related decision making with information model-based digital documents (Doctoral dissertation, University of South Australia).
- [4] O. Curé, M. Lamolle, and C.L. Duc. (2013). Ontology Based Data Integration Over Document and Column Family Oriented NOSQL. arXiv preprint arXiv:1307.2603.
- [5] D. Garets and M. Davis (2012). Electronic Patient Records.
- [6] M. Gertz. Data Provenance/Derivation Workshop, Chicago, 2002
- [7] P.Y. Hsueh, P. Melville, and V. Sindhwani. 2009. Data quality from crowdsourcing: a study of annotation selection criteria. In *Proceedings of the NAACL HLT 2009 Workshop on Active Learning*

for Natural Language Processing (HLT '09). Association for Computational Linguistics, Stroudsburg, PA, USA, 27-35.

- [8] T. Koschmann. Explorations in the Learning Sciences, Instructional Systems and Performance Technologies 2011, [online], Available from: <u>http://hdl.handle.net/123456789/1664</u>
- [9] C. J. McDonald, "The Barriers to Electronic Medical Record Systems and How to Overcome Them", Journal of the American Medical Informatics Association Vol 4(3), May / Jun 1997.
- [10] NHS, "The NHS in England", [online], Available from: http://www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx
- [11] National Information Assurance Glossary http://www.ncix.gov/publications/policy/docs/CNSSI_4009.pdf
- [12] Ph. Moore, F. Xhafa, M. Sharma. Cloud based Monitoring for Patients with Dementia. Chapter to appear in Advanced Technological Solutions for Dementia Patient Monitoring. A book edited by: Fatos Xhafa, Philip Moore, George Tadros. To be published by: IGI Global, Hershey PA, USA, 2014
- [13] C. H. Sin (2008). Developments within knowledge management and their relevance for the evidence-based movement. *Evidence & Policy:* A Journal of Research, Debate and Practice, 4(3), 227-249.
- [14] O. Terzo, P. Ruiu, E. Bucci, F. Xhafa: Data as a Service (DaaS) for Sharing and Processing of Large Data Collections in the Cloud. CISIS 2013: 475-480
- [15] A. E. Vlug, J. Van der Lei, B.T. Mosseveld, M.A.M Van Wijk, P. D Van der Linden, M.C.J.M Sturkenboom, and J.H. Van Bemmel, (1999). Postmarketing surveillance based on electronic patient records: the IPCI project. *Methods of information in medicine*, 38(4/5), 339-344.
- [16] S. Rogerson. (2000). Electronic patient records. IMIS, 10(5).
- [17] R. Navarro. (2008). An ethical framework for sharing patient data without consent. *Informatics in primary care*, 16(4).
- [18] T. Huston. (2001). Security issues for implementation of e-medical records. *Communications of the ACM*, *44*(9), 89-94.
- [19] J. Bergmann, O.J. Bott, D. P. Pretschner, and R. Haux. (2007). An econsent-based shared EHR system architecture for integrated healthcare networks. *International Journal of Medical Informatics*, 76(2), 130-136.
- [20] F. Xhafa, J. Wang, X. Chen, J.K. Liu, J. Li. An Efficient PHR Service System Supporting Fuzzy Keyword Search and Fine-grained Access Control, Soft Computing, Springer. To appear, 2014 a.
- [21] F. Xhafa, J. Li, G. Zhao, J. Li, X. Chen, D. S. Wong. Designing cloud-based electronic health record system with attribute-based encryption. Multimedia Tools and Applications, Springer. *To appear* 2014 b.