Sharing with Care: An Information Accountability Perspective

Randike Gajanayake[1], Renato Iannella[2, 1] and Tony Sahama[1]

[1]Queensland University of Technology,
Brisbane, Australia
[2]Semantic Identity,
Brisbane, Australia.

gajanaya@qut.edu.au, ri@semanticidentity.com, t.sahama@qut.edu.au

Abstract

Health information sharing has become a vital part of modern healthcare delivery. E-health technologies provide efficient and effective ways of sharing medical information, but give rise to issues that neither the medical professional nor the consumers have control over. Information security and patient privacy are key impediments that hinder sharing information as sensitive as health information. Health information interoperability is another issue which hinders the adoption of available e-health technologies. In this paper we propose a solution for these problems in terms of information accountability, the HL7 interoperability standard and social networks for manipulating personal health records.

Keywords: information accountability, healthcare interoperability, e-health, HL7, RIM, EHR, EMR, personal health records, social networks.

1 Introduction

Sharing and proper use of information is an important aspect in modern electronic healthcare. The needs of the present-day medical practitioner, as well as the consumer (patient), are different from what we have seen and experienced in the past. Medical professionals want tools enabling them to connect and share information with other specialists to help make better decisions towards the improvement of the quality of care, and the public (patients) want to be more involved in their own healthcare processes and want control over their health information (health records). Both specialists and patients can benefit from linking family health profiles so that all relevant information is available for reference when the need arises. Information sharing is a part of healthcare that can alter the way in which care is being delivered. But the flow and visibility of health related information among people has to be controlled and monitored to ensure the information will not be misused.

In order to fulfil these needs, we need to consider two aspects regarding information use in healthcare. Firstly, the patients have to be confident that their sensitive information is safe from being disclosed to unwanted parties. Secondly, healthcare interoperability needs to be well understood and properly defined. Information Accountability is a concept that allows the use of information by a person to be monitored and if misused hold that person accountable for the ramifications for his actions. The lack of use of a common healthcare interoperability standard is one barrier to the success of information sharing in healthcare. This paper investigates the role of information accountability and the health information interoperability standard Health Level 7 (HL7) when health information is shared through electronic media among healthcare participants. We propose a solution for sharing and interoperability of health information through the use of a healthcare social network which uses HL7 as the communication method between health information systems.

2 Information Technology and Healthcare

Information Technology adoption in healthcare known as e-health can be better highlighted through the use of personal health records (PHR). In the e-health context this can be subdivided into electronic medical records (EMR) and electronic health records (EHR). The proper implementation of e-Health systems that manipulate EMRs and EHRs is essential to keeping pace with the exponential growth of health information and to applying this knowledge to resolving world health problems.

People have become more and more interested in knowledge of their health and many patients as a result are using the Internet as a means of gaining information about their medical conditions. By doing so they expose (share) their health information to other Internet users who may or may not have the same interests. This creates an entirely different set of issues for the patients other than their medical conditions.

2.1 Information Privacy and Security in Healthcare

The Internet and other communication media often let information be vulnerable to disclosure resulting in security issues and infringement of consumer privacy. Privacy concerns are significant in health informatics and must be addressed at the initial stages of any of its processes. Because of the open architecture of the Internet, special organisational policies and procedures need to be implemented to guarantee the privacy and reliability of e-health systems. These special policies need to be focused on data security as well as other ethical issues pertaining e-health to gain the trust and consent of consumers. As Goldman and Hudson (2000) state, without trusting that their most sensitive health information will be safeguarded, patients are reticent to fully and honestly disclose their personal information and may avoid seeking care altogether.

According to Ann Cavounkian (2010), if privacy is taken into consideration during the development process, there is great potential that these technologies can actually increase the privacy of the individual, by providing them with greater choice and personal control over how their data is managed. Meingast et al. (2006)

says defining clear attributes for role-based access, policy development, rules on patient privacy at home, data mining rules and technological measures will be needed to ensure the security and privacy of medical data. In their effort to solve the privacy problem, Naqvi et al. (2010) has considered a context-aware access control model for assuring privacy of medical records in an Internet based open environment.

As a means of overcoming privacy and security issues related to healthcare, information accountability could prove to be the answer. Transparency and accountability will be critical in helping the society to manage the privacy risks that accumulate from the expeditious progress in communication, storage and search technology.

3 Information Accountability

Accountability is when someone is held answerable for their actions and its outcomes. In other words, accountability focuses on the ramifications after a decision is made. In the context of information accountability, this refers to when one party is held liable to explain, justify or answer for their use of information belonging to another party.

Information is widely available and the use of that information needs to be controlled. Rather than enforcing rigid up-front control over the use of information, there is a need to accommodate "fair use". The control over the use of information is imperfect and exceptions are possible, but violators can be identified and held accountable (Weitzner, Abelson et al. 2008)

3.1 Information Accountability in Healthcare

Accountability has become a major factor in healthcare. Emanuel et al. (1996) focus on three factors that need to be considered to better understand the concept of information accountability in healthcare. It is important to clearly identify the different parties in healthcare that can be held accountable, the issues for which a party can be held accountable and the appropriate mechanisms for accountability, in other words, *who*, *what* and *how*. These can be referred to as the components of information accountability. According to Ferreira et al. (2003), the main objective of accountability systems is to provide a means to verify, analyse and investigate users' actions. Information about parties accountable should be made usable by many stakeholders, each of whom have a different purpose and, therefore, should have different levels of accessibility to the information. The presence of an accountability system tends to ensure procedures are correctly followed.

Figure 1 illustrates the process of information exchange in a general e-health scenario. It illustrates how health information is exchanges between patients and health professionals and between health professionals themselves. Whenever information is used by a health professional they are accountable for the way they used the information. This can be further explained in detail using an e-health scenario.
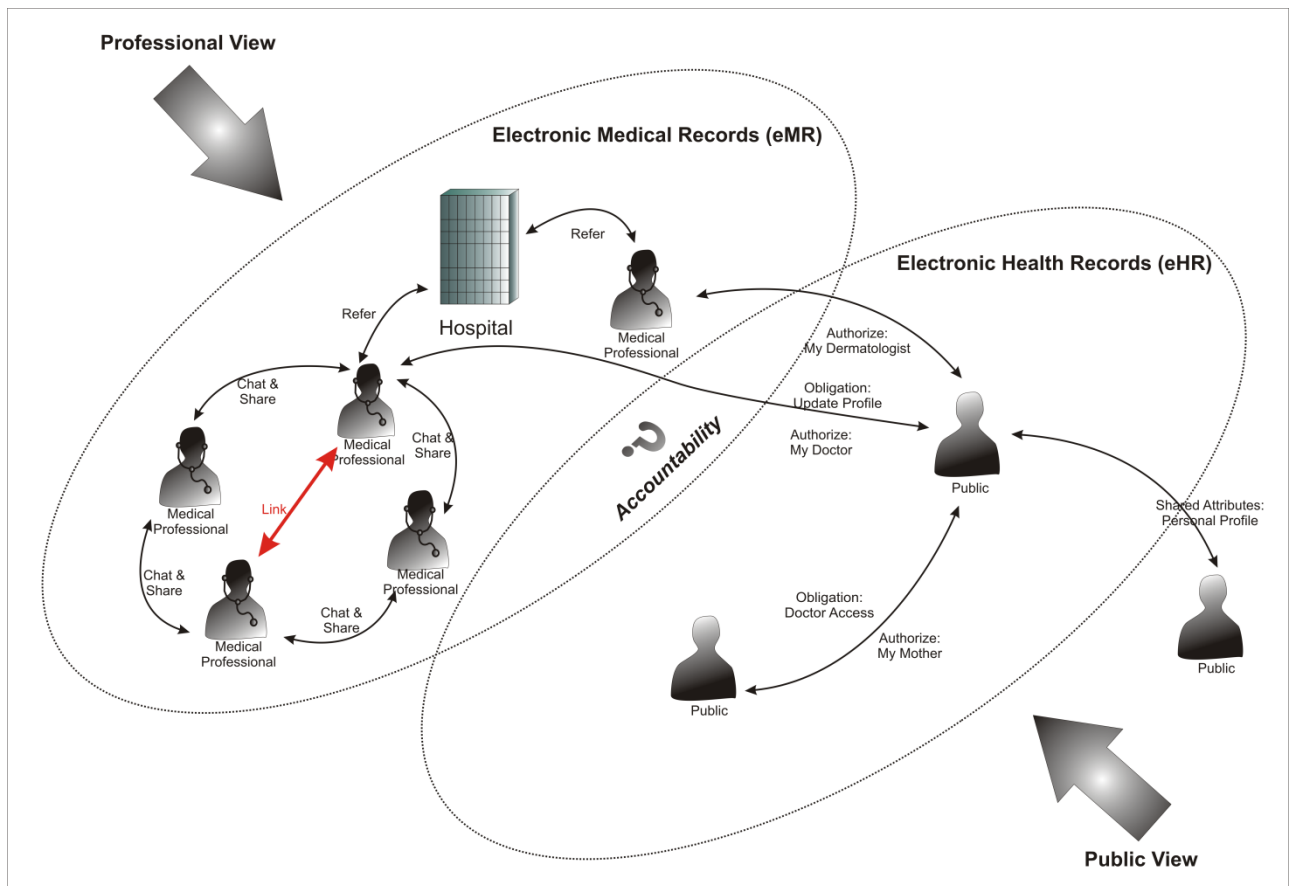

Figure 1: e-Health Scenario of sharing health information

Consider the following e-health scenario. A patient, Gary, who has a personal health record, allows his doctor, Peter, to access his entire health record. Gary also allows his mother to access a portion of the health record, given that she allows Doctor Peter access to related family health information. Doctor Peter participates in discussions with other medical professionals and discusses issues related to Gary without his identity being compromised. This involves sharing Gary's information across many different networks. The "Link" shown in Figure 1 indicates where there is a correlation between interests of both Doctor Peter and another specialist Doctor Claudia. They connect and Doctor Peter exchange further information about Gary with Doctor Claudia. The Accountability system detects that Doctor Claudia has accessed Gary's information and informs him. Since this is for his own wellbeing, Gary allows Doctor Claudia complete access to his health information. Next, Doctor Peter refers Gary to a dermatologist, Doctor Sandra. She is granted access to Gary's health record and also his mother's health records to assist treating a genetic skin condition.

Granting various parties the access to information Gary allows the management and sharing of personal information with his consent and involvement. The need for complex privacy policies is reduced and the policies can be made known to all engaging parties. A use case diagram of this scenario is shown in Figure 2.
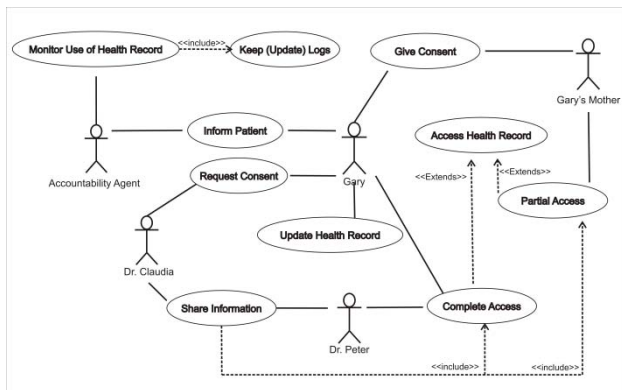

Figure 2: Use Case diagram: e-Health scenario

The Accountability agent is responsible for monitoring and keeping logs on the access to and the use of health records. When sharing patient information, all parties should seek the consent of the patient to do so. The patients will be notified of the use of their information at all times by the Accountability Agent. Alterations to the health records can be done by the patient and/or any other party who has consent of the patient.

Even in an environment with information accountability mechanisms in place, health interoperability to some extent restricts the use of e-health technologies in terms of information exchange between health information systems which is useful when sharing information. Health interoperability arises due to the fact that not all systems use the same format and architecture. This has given rise to many predicaments that has directed the e-health community to seek interoperability standards.

.

3.2 IA and Interoperability

One such standard which is currently in use is the Health Level 7 (HL7) standards for health interoperability. The latest version of HL7 is Version 3 which is based on an Object-Oriented development methodology and a Reference Information Model (RIM). The RIM provides an explicit representation of the semantics and lexical connections that exist between the information carried in the fields of HL7 messages.

The RIM has a backbone structure consisting of three main classes namely Act, Role, and Entity and three associations namely ActRelationship, Participation and RoleLink linked with a number of permitted relationships. The RIM defines a set of Attributes for each class and these are the only ones allowed in HL7 messages. Each attribute has a specific Data Type. These become tags in HL7 XML messages. A subset of the RIM consisting of the six backbone classes with their structural attributes is show in Figure 3.
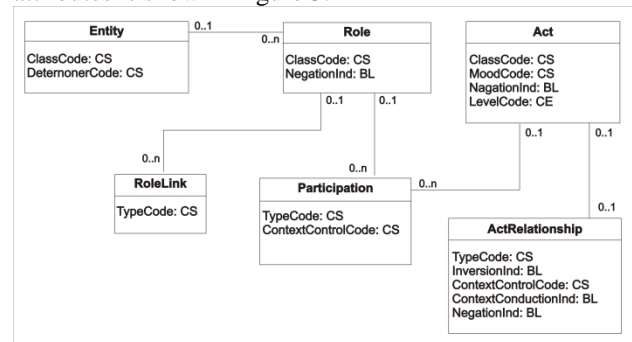

Figure 3: HL7 V3 RIM backbone

Put in plain words, the basic functionality of the RIM backbone classes is as follows; *Act* represents the actions that are executed and these actions must be documented as healthcare is provided. *Participation* expresses the context for an act such as who performed it, for whom was it done, where was it done, etc. *Entity* represents the physical things and beings that are of interest to, and take part in healthcare. *Role* establishes the roles that entities play as they participate in health care acts. *ActRelationship* represents the binding of one act to another, such as the relationship between an order for an observation and the observation event as it occurs. And *RoleLink* represents relationships between individual roles.

```
<observationEvent>
 <id root="someroot" extension="123456" assigningAuthorityName="Springfield Clinic"/>
 <code code="c" codeSystemName="csn" codeSystem="cs" displayName="Glucose
Level"/>
 <statusCode code="completed"/>
 <effectiveTime value="201009231030"/>
 <priorityCode code="R"/>
 <confidentialityCode code="N" codeSystem="some codeSystem"/>
 <value xsi:type="PQ" value="7.0" unit="mmol/L"/>
 <interpretationCode code="H"/>
<referenceRange>
 <interpretationLevelRange>
  <value xsi:type="type">
   <low value="3.6" unit="mmol/L"/>
   <high value="5.8" unit="mmol/L"/>
  </value>
  <interpretationCode code="SET ANY"/>
 </interpretationLevelRange>
</referenceRange>
<author>
  <time value="201009231030"/>
  <modeCode code="WRITTEN"/>
  <signatureCode code="CODE"/>
 <assignedEntity>
   <id root="someroot" extension="123-456-7890"/>
   <assignedPerson>
    <name>
     <given>Bart</given>
     <given>B</given>
     <family>Simpson</family>
    </name>
   </assignedPerson>
 </assignedEntity>
</author>
<recordTarget>
 <patientClinical>
   <id root="someroot" extension="098-765-4321" assigningAuthorityName="Springfield
Clinic Patients"/>
   <addr>
    <streetAddressLine>1 Some Street< /streetAddressLine >
    <city>Springfield</city>
    <postalCode>0000</postalCode>
   </addr>
   <statusCode code="active"/>
   <patientPerson>
    <name use="L">
     <given>Homer</given>
     <given>H</given>
     <family>Simpson</family>
    </name>
   </patientPerson>
 </patientClinical>
</recordTarget>
</ObservationEvent>
```

Figure 4: HL7 V3 message test results snippet

To understand the use of the RIM classes in a real life physician patient encounter, consider the process of a simple measurement of the blood glucose level of a patient. The patient is represented as an instance of class Person and an instance of class Patient, which is a subclass of Role (a Person with the role of Patient). The physician visit is an instance of class PatientEncounter (a subclass of Act). The blood glucose level is an instance of class Observation (a subclass of Act). The patient is linked to the visit by an instance of Participation; the blood glucose measurement is linked to the visit through an instance of ActRelationship. The patient details are recorded at the time the patient registers at the reception of the clinic. Assume that the test is being done by a nurse not the doctor himself using a small hand held device. After the test the results are sent back to the doctor. This information and the results of the test can be used to generate an HL7 V3 message as shown in Figure 4.

In this scenario the patient information will flow from the reception to the doctor and to the nurse who performs the blood test. Since the receptionist, the doctor and the nurse would gain some knowledge about the patients' medical condition; there need to be some mechanism to monitor and record the flow of information and to record the use of information that has been sent to particular entities. The information accountability components which can perform these tasks can be integrated into the HL7 messages that are sent and received from each location. By having these new components integrated within messages, the use of any data element that is sent via an HL7 message will be constantly monitored and recorded. This will require introducing new classes and attributes to the current version of the RIM.

It is important to understand, however, that the RIM, although healthcare specific, is not a model of healthcare. It is also not a model of any message even though it is used in messages.

3.3 Information Accountability and Social Networks in Healthcare

Social networking has become one of the most popular and widely used web applications around the world. Sharing information through a social network and giving patients the control over their information could prove to be very effective in future healthcare needs. According to Domingo (2010), at the moment, healthcare social networks provide an attractive platform for sharing ideas, discussing symptoms and debating treatment options. By allowing medical professionals access to electronic medical records of their patients, this can be taken to the next level and healthcare can be made more efficient and more effective.

According to Harrison and Lee (2006), 86% of people who have access to the Internet have used it to search health related information, 50% of consumers have shown interest in accessing their information through the Internet and 33% considered switching providers so that they can communicate electronically with their physicians. The word 'patient' is slowly transformed into 'consumer' because of the Internet and the demand for a more active role in their own care. Patients do not receive information about their medications. They, therefore, take the matter into their own hands. In her article Domingo (2010) states that 61% of US citizens have looked online for health information in 2008. With this increased interest the demand for better e-health solutions have also increased. Sharing health information through social networks can provide the consumer as well as the health professionals with better and effective means of healthcare capabilities.

Personal health records (PHRs), which can be used to facilitate sharing health information of patients can be integrated in to the structure of the social network itself. These documents can be shared using the HL7 v3 standards to eliminate incompatibility concerns. Information privacy will be the greatest barrier that will need to be overcome. To address this, the best approach,

as discussed earlier, is to introduce an information accountability framework for the proposed PHRs.

Even in popular social networks, privacy is an ongoing subject for debate. In regular social networks the user has the capability to filter the information such that what is displayed can be rigidly controlled by the user. But in healthcare there must be a different mechanism for ensuring privacy since health information must be fully and completely disclosed to the health professionals to allow them to make better decisions. Information accountability can assure the user of secure information sharing and the proper use of information in healthcare. The way information is used has to be monitored and patients as well as the information user must be informed of how information is being used and by whom. This will allow the patients to hold people accountable for inappropriate misuse. Figure 5 illustrates the basic components and the functionality of an information accountability framework that will allow the above operations to be performed.

Patients are not health professionals. For example they are incapable of interpreting an X-ray, a blood test report etc. They also do not have the capability to decide which information is needed for diagnosis purposes and decision making. Hence when health professionals request access to certain health information the patients have to grant them access for that information. But they have to be confident that the information will not be used for any other purpose than what is required. The presence of the information accountability mechanism will make the patients more confident and at the meantime make the information users more aware of the consequences of information misuse.
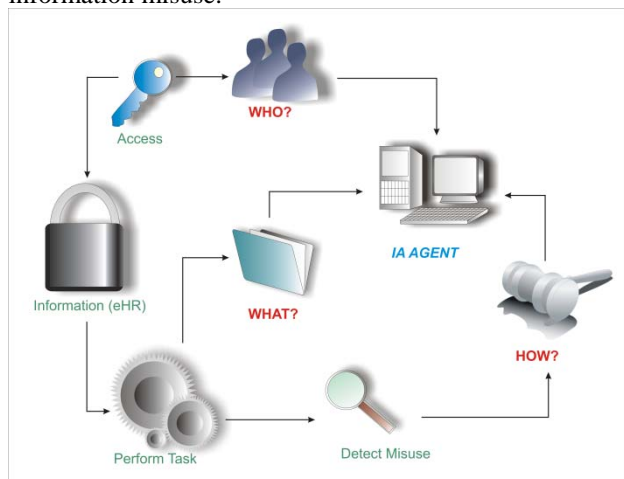

Figure 5: Components of Accountability

In modern social networks these operations are not in place. With the introduction of these capabilities healthcare social networks can benefit both the patients and the health professionals. The public will own their health records and be responsible for the control of their health profiles in the social network. They will be given the opportunity to grant access to the health information to specialists that they feel are suitable for a specific task. The specialists will make further linkages with other medical professionals that will support the ultimate goal of sharing of information, which would leads to better healthcare delivery.

4   Conclusion and Future Work

With proper design and implementation, an integrated solution of the concepts of information accountability and health interoperability in a secure healthcare social network could prove to be the ultimate solution to the impediments that have hindered the progress of e-health as a solution for better patient healthcare. We are currently working on implementing the proposed information accountability framework for health information sharing with the use of HL7 as the medium of communication in a healthcare social network. This will give us the opportunity to validate the framework in a real world information sharing scenario.

5   Acknowledgements

6   References

Cavoukian, A., A. Fisher, et al. (2010). "Remote home health care technologies: how to ensure privacy? Build it in:Privacy by Design." Identity in the Information Society **3**(2): 363-378.

Domingo, M. C. (2010). "Managing Healthcare through Social Networks." Computer **43**(7): 20-25.

Emanuel, E. J. and L. L. Emanuel (1996). "What Is Accountability in Health Care?" Annals of Internal Medicine **124**(2): 229-239.

Ferreira, A., S. Shiu, et al. (2003). Towards accountability for Electronic Patient Records. Computer-Based Medical Systems, 2003. Proceedings. 16th IEEE Symposium.

Goldman, J. and Z. Hudson (2000). "Virtually exposed: Privacy and e-health." Health Affairs **19**(6): 140.

Harrison, J. P. and A. Lee (2006). "The role of e-health in the changing health care environment." Nursing Economics **24**(6): 283-289.

Meingast, M., T. Roosta, et al. (2006). Security and Privacy Issues with Health Care Information Technology. Engineering in Medicine and Biology Society, 2006. EMBS '06. 28th Annual International Conference of the IEEE.

Naqvi, S., G. Dallons, et al. (2010). Assuring Privacy of Medical Records in an Open Collaborative Environment - A Case Study of Walloon Region's eHealth Platform. Privacy and Identity Management for Life. M. Bezzi, P. Duquenoy, S. Fischer-Hübner, M. Hansen and G. Zhang, Springer Boston. **320:** 146-159.

Weitzner, D. J., H. Abelson, et al. (2008). "Information accountability." Commun. ACM **51**(6): 82-87.

Authors

Randike Gajanayake

Randike is a postgraduate research student at the Faculty of Science and Technology at Queensland University of Technology, Brisbane, Australia. He holds a degree of Bachelor of Science (Special in Computer Science) from the University of Peradeniya, Sri Lanka. His research interests lie in the fields of e-health, medical image processing and Algorithms.

Postal Address:

Queensland University of Technology,

Level 10, 126 Margaret Street,

Brisbane, 4001,

AUSTRALIA.

Phone: +61-7-3191 8821

Mobile: +61-4-5833 3320

Email: gajanaya@qut.edu.au

Renato Iannella

Renato is an independent Semantic Web Science Technology Strategist and Adjunct Professor at the Queensland University of Technology (QUT). His research and technologies experience covers the Semantic Web, Web Science, Social Networks, & Rights and Privacy Management. Renato also has extensive experience in Information Standards for Internet, Web and Mobile platforms. Renato was also the Founder and is the Convener of the ODRL Initiative which develops and promotes industry strength rights languages for open and commercial sectors.

Renato also is a Visiting Professor at the University of Hong Kong, Adjunct Associate Professor at the University of Queensland, and Technology Strategist at Peepel. He previously was Principal Scientist at the National ICT Australia (NICTA) research laboratory, Chief Scientist at IPR Systems & LiveEvents Wireless, Principal Research Scientist at the Distributed Systems Technology Centre (DSTC), and was a former member of the World Wide Web Consortium (W3C) Advisory Board.

Postal Address:

Semantic Identity,

316 Brisbane Corso, Yeronga,

Queensland, 4104,

AUSTRALIA.

Phone: +61-7-3892 6961

Mobile: +61-4-1313 2206

Email: ri@semanticidentity.com

Tony Sahama

Dr. Tony Sahama is a Senior Lecturer in the Computer Science discipline at the Faculty of Science and Technology (FaST). He holds a PhD in Computer Simulation and Modeling. He is an active member of the Computer Science discipline on teaching and research. Tony's research contribution is not limited to his research area of interest in the Medical Informatics domain. He also spends a considerable time on Teaching and Learning research as well. Currently he is supervising several Medical Informatics related HDR student projects. Since 2009, Tony holds the SCEPTrE (UK) Teaching fellowship as part of his Work Integrated Learning (WIL) industry collaborative work.

Postal Address:

Queensland University of Technology,

Level-10, 126 Margret Street,

Brisbane, 4001,

AUSTRALIA.

Phone: +61-7-3138 1131

Fax: +61-7-3138 9390

Email: t.sahama@qut.edu.au