DRIVING REFORM: DIGITAL HEALTH IS EVERYONE'S BUSINESS

Studies in Health Technology and Informatics

This book series was started in 1990 to promote research conducted under the auspices of the EC programmes' Advanced Informatics in Medicine (AIM) and Biomedical and Health Research (BHR) bioengineering branch. A driving aspect of international health informatics is that telecommunication technology, rehabilitative technology, intelligent home technology and many other components are moving together and form one integrated world of information and communication media. The series has been accepted by MEDLINE/PubMed, SciVerse Scopus, EMCare, Book Citation Index – Science and Thomson Reuters' Conference Proceedings Citation Index.

Volume 214

Recently published in this series

ISSN 0926-9630 (print)
ISSN 1879-8365 (online)

Driving Reform: Digital Health is Everyone's Business

Selected Papers from the 23rd Australian national Health Informatics Conference (HIC 2015)

Edited by

Andrew Georgiou

Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

Heather Grain

E-Health Education, Melbourne, Australia

and

Louise K. Schaper

Health Informatics Society of Australia, Melbourne, Australia

IOS Press

Amsterdam • Berlin • Tokyo • Washington, DC

ISBN 978-1-61499-557-9 (print)
ISBN 978-1-61499-558-6 (online)
Library of Congress Control Number: 2015946211

Publisher
IOS Press BV
Nieuwe Hemweg 6B
1013 BG Amsterdam
Netherlands
fax: +31 20 687 0019
e-mail: order@iospress.nl

Distributor in the USA and Canada
IOS Press, Inc.
4502 Rachael Manor Drive
Fairfax, VA 22032
USA
fax: +1 703 323 3668
e-mail: iosbooks@iospress.com

PRINTED IN THE NETHERLANDS

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

Preface

Healthcare planners and governments across the globe are involved in efforts to stimulate innovation and to reform health systems as a means of enhancing the delivery of safe, effective and quality care to patients. Information and communication technology (ICT) is a critical component of health system innovation and a key stimulus for reform. This is because the introduction of ICT is much more than just a technical task, it involves new ways of working, networking and organising globally. The Health Informatics Society of Australia (HISA) with the support of the Australasian College of Health Informatics (ACHI) have continued to be in the forefront of efforts to promote ICT-enabled healthcare reform and innovation in Australia. The Australian National Health Informatics Conference (HIC) is Australia's premier health informatics event bringing together researchers, industry groups and healthcare providers from Australian and internationally, providing the opportunity to display and share cutting edge research evidence, technology updates and innovations.

The theme for HIC 2015 is "Driving reform: Digital health is everyone's business". The conference highlights the role that health informatics can play in the development of a smart digital healthcare system to drive reform and to meet increasing demands and financial pressures. In today's environment health services are being increasingly technology-enabled so as to:

- Address increasing consumer demands and expectations
- Provide relevant, appropriate and effective real-time information to clinical practitioners
- Enhance the management and monitoring of healthcare delivery performance

The papers in this volume provide valuable research evidence and information about the diverse role that ICT plays in the health, aged and community care sectors, across Australia, New Zealand and internationally. The papers represents a wide spectrum of work encompassing major theoretical concepts, examples of key applications of new technologies and important new developments in the field of health informatics. Taken together the volume makes an important contribution to the health informatics evidence base and the quality development of ICT.

This year's Health Informatics Conference continues and augments the double blind peer review process established in 2011 in a previous volume. All papers were reviewed by three experts in the field of health informatics, selected as prominent academics and industry specialists. The assistance of the Australasian College of Health Informatics in supporting this process through the voluntary efforts of its Fellows is gratefully acknowledged, as is the contribution made by many senior and experienced members of the Health Informatics Society of Australia. This phase of reviewing resulted in the provisional acceptance of 26 from a much expanded submission field of 51 papers. The Scientific Program Committee then undertook a validation process for all such papers that were resubmitted in amended form, to ensure that reviewers'

recommendations were appropriately addressed or rebutted. In total 26 papers were included in this volume. Congratulations to all the authors of the papers in this volume.

Andrew Georgiou
Heather Grain
Louise K. Schaper

Acknowledgements

The Editors wish to thank the following people for their efforts in reviewing the papers submitted for HIC 2015.

A/Prof Andrew Georgiou, Macquarie University
A/Prof Heather Grain, E-Health Education
Dr Jim Basilakis, University of Western Sydney
Dr Melissa Baysari, Macquarie University
Vicki Bennett, Vicki Bennett Consulting
Dr Jen Bichel-Findlay, University of Technology Sydney
Heidi Bjering, University of Western Sydney
Neville Board, Australian Commission on Safety & Quality in Health Care
Dr Andy Bond, National E-Health Transition Authority
Dr Douglas Boyle, University of Melbourne
Ian Bull, ACT Health
Dr Kerryn Butler-Henderson, University of Tasmania
A/Prof Joanne Callen, Macquarie University
Paul Clarke, JamPac Health Informatics Management Consulting
Bernard Crowe, Bernard Crowe & Associates
Dr Ambica Dattakumar, University of Melbourne
Dr Karen Day, University of Auckland
Cathy Doran
Dr Juanita Fernando, Monash University
Joanne Foster, Queensland University of Technology
Janette Gogler, Bendigo Health
Prof Andrew Grant, Université de Sherbrooke, Québec
Dr Kathleen Gray, University of Melbourne
Dr Helen Gu, University of Auckland
Dr David Hansen, The Australian E-Health Research Centre, CSIRO
Dr Jennifer Hardy, University of Sydney
Christian Hay, GS1 – The Global Language of Business
Leanne Holmes, Holmes Health Information
Dr Michael Lawley, The Australian E-Health Research Centre, CSIRO
A/Prof Michael Legg, Michael Legg & Associates
Elin Lehnbom, Macquarie University
Dr Hugo Leroux, The Australian E-Health Research Centre, CSIRO
Dr Hugh Leslie, Ocean Informatics
Amy Mayer, North Metro Health Service Mental Health
Simon McBride, The Australian E-Health Research Centre, CSIRO
Dr Vince McCauley, IHE Australia
Prof Jon Patrick, Health Language Analytics-iCIMS
Dr Mirela Prgomet, Macquarie University
Dr Magdalena Raban, Macquarie University
Derek Ritz, EcGroup Inc

Sarah Ryan
Dr Basema Saddik, King Saud Bin AbdulAziz University for Health Sciences
Dr Antony Sara, South Eastern Sydney Local Health District
Dr Philip Scott, University of Portsmouth
Prof Jeffrey Soar, University of Southern Queensland
Prof Paula Swatman, University of Tasmania
Alan Taylor, eDevelopment Solutions
Donna Truran, The Australian E-Health Research Centre, CSIRO
Dr Chandana Unnithan, Victoria University
A/Prof Klaus Veil, University of Western Sydney
Prof Jim Warren, University of Auckland
Dr Sue Whetton, University of Tasmania
A/Prof Patricia Williams, Edith Cowan University
A/Prof Ping Yu, University of Wollongong

Contents

This page intentionally left blank

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-1

HL7 Middleware Framework for Laboratory Notifications for Notifiable Diseases

Mehnaz ADNAN, Donald PETERKIN, Aaron MCLAUGHLIN and Nicholas HILL
Institute of Environmental Science and Research, Wellington, New Zealand

Abstract. LabSurv is an electronic notification system developed to support laboratories to directly notify the results of notifiable disease testing to public health services in New Zealand. A direct laboratory notification middleware framework was developed to manage the information flow between laboratories and public health services. The framework uses an HL7 messaging standard to receive the laboratory results and windows services to integrate the results with the cases of notifiable diseases within a national electronic surveillance system. This paper presents the system design and implementation details of direct laboratory notification system in LabSurv. It presents the HL7 messages structure implemented in the system. Finally, the performance of the system based on implemented framework is analysed and presented to evaluate the efficiency of our design.

Keywords. HL7, Laboratory Results, Public Health

Introduction

In New Zealand, medical practitioners have been required to report the cases of specified infectious diseases for over 100 years. Currently, 85 diseases are "notifiable" to a Medical Officer of Health in New Zealand [1]. Initially, the notifier was required to complete a specified form and send it by post to the local District Health Officer. Throughout the years, the delivery of this information has been systemised, in 2007, a secure web-based real time national disease surveillance system – EpiSurv – was deployed. EpiSurv enables Medical Officers of Health or other public health staff to record notifiable disease case details from clinicians in the national database and provides real time access to data for analysis at the national level [2]. EpiSurv is currently used by 20 Public Health Units (PHUs) throughout New Zealand, with 150 registered users. EpiSurv provides a robust and secure information management platform to deliver integrated and timely information to its stakeholders and end users.

In December 2007, new legislation for reporting of notifiable diseases by laboratories was enacted in New Zealand [3]. This new legislation required laboratories to report the results of tests for specified diseases directly to the Medical Officers of Health for that region. This legislation enhanced the current reporting by clinicians and provided comprehensive and timely information to Medical Officers of Health. In order to ensure information flow between laboratory systems and EpiSurv, an electronic reporting system – LabSurv – was developed as the technical backbone to support laboratories in notifying the data about communicable diseases [4]. LabSurv has been

in full service since March 2008. The application adapts the HL7 Radiology and Pathology Messaging standard for data exchange and a middleware framework to integrate data into EpiSurv allowing notifying laboratories to electronically transmit patient results to a Medical Officer of Health.

This paper presents the technical aspects of the HL7 middleware framework implemented for electronic data transfer of laboratory results within the surveillance system. The objective of this paper is to present technical solutions developed in New Zealand which could be applicable in surveillance systems of other countries or international networks. In the following sections we will describe the requirement, design, implementation and performance of our middleware framework.

1. System Requirements

The most important task of developing a health information system is to design the architecture for exchanging various medical information and data across systems. In the architecture design of LabSurv, several requirements have to be met while choosing and defining the standards to be used in our system. First, the system should be designed to be operated by laboratory staff and PHU staff. Hence, interfaces would be needed to exchange data electronically using existing national health information systems, laboratory information systems and EpiSurv. Second, the software architecture must be able to store the results in a solution, eliminating the need for users to manually enter data relating to the notification. Where appropriate, details from the electronic notification will be mapped into a case report form, avoiding the need for manual data entry. PHUs will be able to extract all data generated for their PHU for use in their local systems used to support their information needs for notifiable diseases. Third, new laboratory-reported cases are visible to local public health staff members who are then able to reconcile lab information with an existing notification for a patient. For example, if a corresponding physician report record does not already exist within the database a new case record is generated and allow a Medical Officer of Health to modify, close and delete the case. Finally, the national surveillance system i.e. EpiSurv would be the master source of the core data for notifiable diseases reflecting any change in the case status.

2. System Design and Implementation

To meet the above requirements, the end to end laboratory notification process is defined as follows:

Step 1. The clinician examines the patient, identifies the possibility of presenting symptoms of a notifiable disease.

Step 2. Sends patient to submit a sample for a laboratory test.

Step 3. The laboratory performs tests, if the criteria for notification are met then the laboratory generates and transmits an electronic message to LabSurv.

Step 4. LabSurv processes the message in real time and makes it available on EpiSurv as a notification to be viewed and actioned by the relevant Medical Officer of Health.

Step 5. The laboratory sends the test results in a report form back to the ordering clinician.

2.1. System Architecture

A middleware framework was designed to implement the end to end laboratory notification process and to meet the requirements as outlined in section 1. Figure 1 provides a high level overview of the direct laboratory notification (DLN) architecture in LabSurv designed to receive and update the notification data in EpiSurv. In this architecture, a laboratory receives a test request and undertakes the tests requested. If a lab result is positive for a notifiable disease, the laboratory information system sends a notification message in HL7 format to LabSurv. The message broker receives the valid message, passes the message to direct laboratory notification middleware in LabSurv and send a message acknowledgement back to the laboratory information system. The role of the message broker is to manage laboratory notification messages to ensure they meet the minimum data set standard and securely passed between the laboratory and the LabSurv. In DLN middleware, the HL7 handler module consist of two windows services, a message receiver and a message parser. The message receiver service receives the message and stores the raw message in the message store and passes the message copy to parsing module. The parsing module is implemented using Java Composite Application Platform which parses the required information from HL7 message and stores the notification information in the Notification database. A matching module attaches the notification information to a corresponding case in EpiSurv if it already exists, based on a match of key patient identifiers or creates a new case from information contained in the notification. The Medical officer of health accesses new notifications through the 'notifications module' on EpiSurv via a web browser at their PHU.

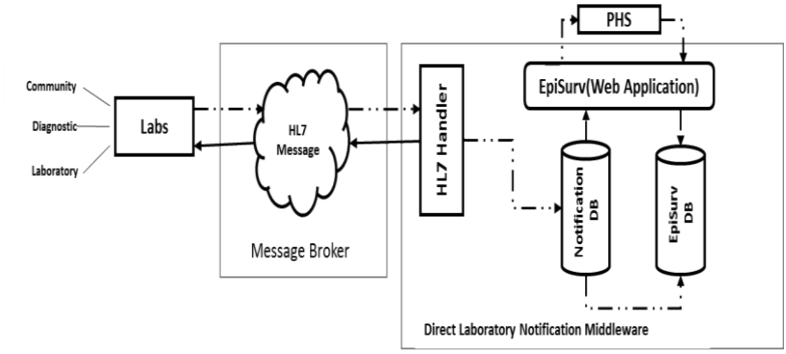

Figure 1. Direct Laboratory Notification Architecture in LabSurv.

2.2. HL7 Message Specifications

Message specifications have been developed based on information requirements for disease notification. This information includes demographic information for the patient, relevant clinical information and test results. Two types of messages are included. One is ORU laboratory results message, which is used for receiving notification from laboratory systems and other is ACK response message, which is used to send the

acknowledgement or rejection to message sender. Table 1 shows the segments of ORU and ACK messages.

In ORU laboratory results message, PID segment is used to include patient identification such as National Health Index number. PV1 is used to convey notification number. The OBR segment is used to record the details of sample, testing ordering clinician and the reporting public health unit. The OBX segment is used to record the disease notification type and test results. A specific LOINC code is used to identify the OBX segment that contains the disease notification type. The NTE segment is used to record any comment in free text format. The MSA segment is used only in version 2.1 message to send the acknowledgement response. The receiver only process MSH, PID, PV1, OBR, OBX and NTE segments and discards other segments, if any. In ACK response message structure, MSH is the message header, MSA is the acknowledgement section and ERR is the error code in case of any error occurred.

Table 1. HL7 message types and their segments in DLN.

ORU laboratory results message		**ACK response message**	
Segment Name	*Description*	*Segment Name*	*Description*
MSH	Message Header	MSH	Message Header
MSA	Message Acknowledgement	MSA	Message Acknowledgement
PID	Patient Identification	ERR	Error
PV1	Patient visit		
OBR	Order detail		
OBX	Observation/result		
NTE	Notes and comments on results information		

These messages comply with NZ Health Information Standards Organisation, HISO, standards [5]. Currently, 33 laboratory sites are sending notifications compliant with HISO HL7 standard v2.4 and one complies with v2.1.

3. Performance Analysis

This section presents an analysis of system usage in the process of attaching laboratory notification to case. We collected the HL7 messages received by the DLN middleware framework between January and December 2014. Table 2 shows the monthly statistical analysis of total laboratory notifications created in EpiSurv by the DLN system. “Not a New Case” represents that a case is present in EpiSurv at the time of notification being created. “New Case” represent that the cases have been initially created from direct laboratory notification. “Confirmed” represent that the case created by DLN was confirmed by Medical Officer of Health and “Not a Case” means that the created case was found to be an invalid case after further investigations by Medical Officer of Health. A total of 17962 notifications were received from which 7946 new cases of

notifiable diseases were created. Out of these new cases 6162 cases were confirmed by Medical Officer of Health. 10016 notifications are attached to existing cases, providing laboratory results for case management and public health action.

Table 2. Direct Laboratory Notification Statistics for 2014.

Month	Not New Case	New Case (Confirmed, Not a Case)	Total Notifications
January	836	774 (606, 119)	1610
February	851	609 (482, 94)	1460
March	808	635 (489, 115)	1443
April	746	496 (394, 77)	1242
May	776	601 (463, 106)	1377
June	774	535 (404, 98)	1309
July	814	652 (463, 155)	1466
August	717	614 (487, 95)	1331
September	941	658 (508, 114)	1599
October	1090	819 (630, 136)	1909
November	800	782 (614, 129)	1582
December	863	771 (622, 134)	1634
Grand Total	10016	7946 (6162, 1372)	17962

Figure 2 shows the total number of notifiable disease cases identified and the total number of new confirmed cases created from direct laboratory notifications for each month in the year 2014, with a minimum of 48.18% and maximum of 55.95% new cases (with an average of 51.09%) created from the messages received directly by LabSurv during January to December 2014. The trend lines shows a linear relation between EpiSurv case count and the new confirmed cases created via LabSurv.

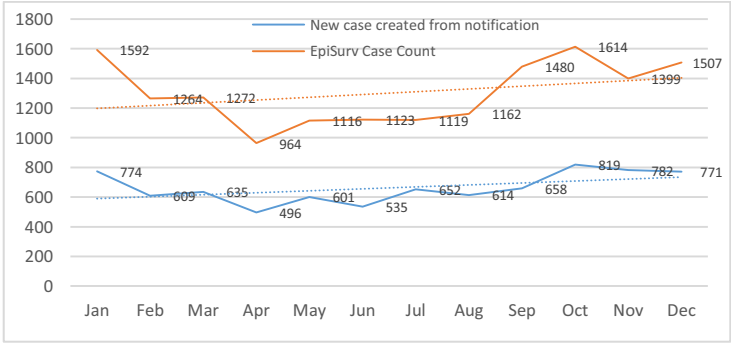

Figure 2. Trend of EpiSurv Cases and New Cases Created from Direct Laboratory Notifications.

Figure 3 shows the time taken between receiving the notification message by HL7 handler, parse the information and attach it to an existing case. Figure shows that, 26.8%, 60.9% and 75% of messages were processed in maximum of 10, 20 and 30 seconds respectively.

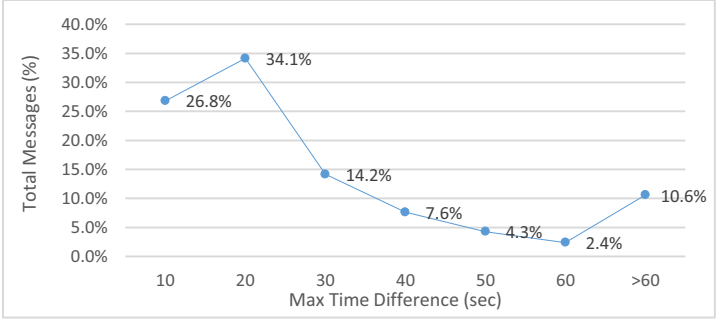

Figure 3. Time Taken by Messages to Process.

4. Discussion and Conclusion

In this paper, a middleware framework for transferring laboratory results to national electronic surveillance system using an HL7 standard and windows services is presented. The HL7 and windows service framework has provided an effective solution for the challenges of integrating various and heterogeneous information systems while developing a large scale health information system. The system is found to be an effective tool to be used in conjunction with the national reporting system and currently creating an average of 51% of notifiable disease cases automatically from the data collected from HL7 messages. 75% of messages were processed within 30 seconds of receipt from message broker providing a near-real time reporting of notifiable infectious disease of public health significance.

There are limitations in performance and use of LabSurv. In terms of performance, a time delay of more than 30 seconds is attributed to windows services which run in batch mode and resulting in a short delay of notification processing. This is being addressed by replacing the services and message broker to Orion Health Ltd.'s Rhapsody Integration Engine [6]. The system does not currently extract laboratory details for example pathogens and their subtypes from laboratory results and place it into EpiSurv case reports. This is primarily because the system is using HL7 version 2 which has limitations in defining data fields to encompass broad range of health information and vocabulary [7]. This may be addressed in future, but is dependent on changes in the way laboratories structure test results within the OBX segment, which could be largely dependent on the implementation of laboratory data standards. While the LabSurv system has been widely adopted, its use is not mandatory and not all Laboratories in the country send their notifications electronically, with community laboratory providers continuing to use alternative manual and bespoke methods of notification to local public health units. A programme of work is underway to work

with Laboratory Information System vendors to enable their system to send notifications electronically.

The current study is focused on the technical component of the system, therefore the system is evaluated to measure its efficiency in processing the notifications in a real time manner. LabSurv has also allowed laboratories and public health unit to adopt digital methods of information management, rather than the informal and fax based methods used previously. A further evaluation of the system with PHUs would be useful to measure its impact on public health.

References

[1] Ministry of Health, New Zealand, "Notifiable diseases: diseases that are notifiable to the medical officer of health", ed. Ministry of Health, Wellington, New Zealand, 2012.
[2] Institute of Environmental Science and Research. *EpiSurv*. Available: https://surv.esr.cri.nz/episurv/index.php
[3] Ministry of Health, New Zealand, "Directory laboratory notification of communicable diseases: national guidelines," ed. Ministry of Health, Wellington, New Zealand, 2007.
[4] Institute of Environmental Science and Research. *LabSurv*. Available: https://surv.esr.cri.nz/LabSurv/index.php
[5] Health Information Standards Organisation (HISO), "Health Level 7 (HL7) endorsement," ed, 2005.
[6] Orion Health. *Rhapsody Integration Engine*. Available: https://www.orionhealth.com/rhapsody-integration-engine
[7] C. N. Mead, "Data interchange standards in healthcare it-computable semantic interoperability: Now possible but still difficult. do we really need a better mousetrap?," *Journal of Healthcare Information Management,* vol. 20, p. 71, 2006.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-8

A Registry Framework Enabling Patient-Centred Care

Matthew I. BELLGARD [a,b,1], Kathryn NAPIER [a], Lee RENDER [a], Maciej RADOCHONSKI[a], Leanne LAMONT[c], Caroline GRAHAM[c], Steve D. WILTON [a,b], Sue FLETCHER [a,b], Jack GOLDBLATT [e], Adam A. HUNTER [a] and Tarun WEERAMANTHRI [d]

[a] *Centre for Comparative Genomics, Murdoch University, Perth, Western Australia*
[b] *Western Australian Neuroscience Research Institute, Perth, Western Australia*
[c] *Office of Population Health Genomics, Public Health Division, Department of Health, Government of Western Australia, Perth, Western Australia*
[d] *Public Health Division, Department of Health, Government of Western Australia, Perth, Western Australia*
[e] *Genetic Services of Western Australia, King Edward Memorial Hospital, School of Paediatrics and Child Health, University of Western Australia, Perth, Western Australia*

Abstract. Clinical decisions rely on expert knowledge that draws on quality patient phenotypic and physiological data. In this regard, systems that can support patient-centric care are essential. Patient registries are a key component of patient-centre care and can come in many forms such as disease-specific, recruitment, clinical, contact, post market and surveillance. There are, however, a number of significant challenges to overcome in order to maximise the utility of these information management systems to facilitate improved patient-centred care. Registries need to be harmonised regionally, nationally and internationally. However, the majority are implemented as standalone systems without consideration for data standards or system interoperability. Hence the task of harmonisation can become daunting. Fortunately, there are strategies to address this. In this paper, a disease registry framework is outlined that enables efficient deployment of national and international registries that can be modified dynamically as registry requirements evolve. This framework provides a basis for the development and implementation of data standards and enables patients to seamlessly belong to multiple registries. Other significant advances include the ability for registry curators to create and manage registries themselves without the need to contract software developers, and the concept of a registry description language for ease of registry template sharing.

Keywords. Disease registry, patient-centred care, data elements, registry description language

Introduction

Patient-centric information resources (or registries) are essential [1] [2] [3] [4] [5] [6]. With the focus of health care reform turning to patient-centred care, registries become even more critical. Patient-centred care is defined as care that is "respectful of and

[1] Corresponding Author: Matthew I. Bellgard, Centre for Comparative Genomics, Murdoch University, Perth, Western Australia, 6150; E-mail: mbellgard@ccg.murdoch.edu.au.

responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" [7]. The challenge then becomes the ability to dynamically assess to what extent patient-centred care is part of routine care in order to influence clinical decision making [8]. To achieve this, it is recognised that diagnosis begins with standardised data collection [9] and in this regard, appropriate patient registry design and implementation is crucial as a core enabler.

Registries come in many forms: disease-specific, recruitment, contact, clinical trial, post market and surveillance. In a rare disease context, patient registries must operate across jurisdictions and country borders. It is also expected that they interoperate with other registries, biobanks and most critically, electronic health records [6]. Unfortunately, the majority do not. Disease registries are typically stand alone, developed for different computer platforms, designed and implemented to different software development quality standards, implement varying levels of security, and are often times locked-in to proprietary data standards and system technologies rather than open standards. There are international efforts designed to harmonise these legacy systems such as the European Union Framework 7 project, RD Connect, which is an integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research – http://rd-connect.eu).

Registries by their very definition become enduring information repositories that must be accessible and functional well beyond the life of funded initiatives. However, given project funding cycles and competitive research, registries are typically not interoperable, unnecessarily duplicated, and the data captured within these systems are not amenable to be linked easily to other important information resources. In a previous study, we proposed a checklist for stakeholders wishing to implement or deploy a registry system. In this checklist we identified key criteria for consideration such as technology choices, system design, security, sustainability, interoperability [4] to assist in strategic planning. We also discussed the term 'interoperability'. Unfortunately, with standalone registry systems, tedious manual and repetitive data exchange still occurs between them. NATO outlined four levels/Degrees of interoperability and we stated that patient registries must adopt Degree 3 and/or 4, seamless sharing of data, and seamless sharing of information, respectively [4]. Serious consideration must also be given to legacy systems to determine if the effort required to support, curate and extract information via manual methods weighs up against investment in migrating to a superior system with automated and interoperable processes.

It is recognised that registry requirements can evolve over time. For example, a registry may begin its life as a contact registry and then become a disease-specific one. If the software architecture cannot support this evolution, then this leads to separate registry creation and fragmentation [4]. We contend that designing and implementing an open source patient registry framework rather than just a single registry is a viable solution that can lead to achieving these higher degrees of interoperability [2] [4] [5] [6]. We provide an overview of this framework, its features and its development roadmap – ultimately to not just capture information but to become a useful knowledge management tool for patient-centred care.

1. Overview of Patient-Centric Registry Framework

The Registry Framework (RF) allows scientists and registry curators with standard computing skills to dynamically construct a complete patient registry from scratch, and

customise it for their specific needs, with little or no need to engage a software developer at any stage. New data elements for a diverse range of phenotypic and genotypic features can be defined at any time and can then be utilised and reused in any of the created registries. Fine grained, multi-level user and workgroup access can be applied to each data element to ensure appropriate access and data privacy. A number of key features of this framework are listed in Table 1. While this is not an exhaustive list, it includes desirable features, such as the ability to create multiple registries, patients being defined once but belonging to multiple registries, and the ability for curators to create data elements dynamically, well after the registry has been defined, enabling the registry to adapt to the evolving requirements of data capture.

Of particular interest is that within the RF, a registry created is defined by a description language. A standard patient registry can now be defined in a standardised, concise way. For example, the myotonic dystrophy (DM1) registry (excluding data elements) can now be encoded in just in just over 200 lines of computer-readable text [5] as opposed to the same registry implemented in a programming language (standalone) using 5000 lines of programming code [2] [4]. This definition file can be imported, exported, versioned and stored in a shared accessible environment [5]. Patient consent is captured through data elements, and while it can be customised as required, an example three level consent is currently in place: i) the patient consents to be part of the registry and have data retained and shared in accordance with the information provided to them; ii) the patient consents to be contacted about clinical trials or other studies related to their condition; and iii) the patient consents to be sent information on their condition.

1.1. Data Element Specification

Data element (DE) is a term used to define physiological measurements such as date of birth, body mass index, genotype, and so forth. Significant work has been undertaken to define data elements common to a class of diseases [1] [10]. While there are definitions for common data elements, for those that are common/specific to a given disease, a data element specification is required to be implemented. Not surprisingly, data elements currently implemented within patient registries are not sharable or reusable in other systems.

To date, the typical way to 'share' data elements (DE) is to share the names of the fields, usually captured in a spreadsheet. Unfortunately, this does not capture the DE specification details. If a DE specification existed, it would then be possible to share and exchange these definitions in a standardised way. In Table 1, we show that a data element can be an integer, float, string, date, range of values (permissible values), describe a file to be uploaded (e.g. a consent form) or be derived (calculated) from other data elements, referred to as derived data elements (DDE) [5]. It is possible to apply validation rules (min/max) for numeric fields, pattern validation for textual fields (such as health care card patterns) and to develop consistent graphical user interface (GUI) components for specific DEs. Within the RF, DEs and DDEs are described in a description file; they can be shared and most importantly, reused in other registries. In terms of the specification, a DE is made up of three sections, header, definition and ontology. A number of operations are possible as a result of this data element specification. For instance, a permissible value group (PVG) called *Size* can be specified with permissible values (PVs): (*large*, *medium*, *small*). Two different range DEs might use the same *Size* PVG. This level of abstraction ensures that both PVGs

and DEs are not tied to any single registry definition and can be reused easily in multiple registries.

1.2. Current Deployments

The RF is currently deployed for clinical-based, patient organisation-driven registries: DMD (live), SMA (live), DM1 [2] [4]. A number of other international and national disease registries driven by clinicians, patient advocate groups, patient wellbeing – surveillance and industry are in preparation for deployment.

2. Discussion: Future Directions of the Registry Framework

The framework design principles are to transform a registry to a knowledge management system, rather than merely an information capture system. We outline key directions of the RF development roadmap that facilitate this transformation.

2.1. Online Sharable Data Element Definition Resource

A registry consists of forms, sections and data elements contained within. It is possible to share and reuse forms and sections of previously created registries, as a definition file is generated for each registry. There will be a search capability to allow users to find previously defined registries, forms, sections and data elements. There is an upload section to allow data elements created by third parties to be shared. Data elements specification can now be shared. We are creating an online environment to store data elements that have already been developed. These data elements will be tagged in a fashion to enable them to be structured within a given data element ontology, such as according to NINDS common data element format [10].

2.2. Interoperability between Data Elements and Electronic Health Records

An important consideration for data elements is their interoperability, not just with other registries but with electronic health records (EHR). Fortunately, an ISO standard exists for data elements used within an EHR (CEN/ISO EN13606). Within an EHR context, the concept of a DE equivalent is referred to as Archetypes and we are defining our patient registry DE specification to be consistent with the Archetype model. Through this alignment, it is then possible to seamlessly exchange data between systems.

3. Conclusion

Interoperable disease registries underpin patient centred care, as is evidenced for rare disease patient care. In this manuscript we provided an overview of a registry framework that enables seamless adherence to not only common data standards, but also outlines a standard registry definition description language. This standard definition language is used to define components of a registry, namely, forms, sections, data elements and permissible value groups, for ease of sharing and adoption. It is then

possible for new groups to utilise an existing definition file to create a new registry or add new components to an existing registry compatible with other international/national registries. All this can be achieved without the need to engage with software developers. Finally, the commitment to open standards enables extensions to the framework to incorporate workflow modules to support models of care, notifications/reminders for clinicians. We have prototyped a clinical adjudication workflow within the framework that has multiple applications. In this way, the registry framework becomes a modular knowledge management system.

Table 1. Key features of the Registry Framework.

Feature	Description
Dynamic Creation of Data Elements (reusable fields)	Users of the RDRF (typically assigned administrators) have the ability to add new Data elements.
Data element support for various "abstract data types"	Framework supports: String (allows pattern matching/restrictions to be imposed); integer (with max/min); range (list/permissible values); calculated (functions); file (upload/download); float (real/decimal numbers); alphanumeric; Boolean (true/false presented as a check box).
Dynamic creation of a Registry	More than one Registry per web site is possible.
Dynamic Creation of Registry Forms	A Registry is made up of many Forms and each form is made up of Form Sections.
Dynamic creation of Questionnaire page for a Registry	Nominating a form as a questionnaire exposes the form on a public URL. The data captured by the form is stored as a "questionnaire response" which when approved by a curator, creates the patient record and also updates the clinical data record for the new patient.
Export Registry Definition File	A Registry is defined in Registry Definition File. This file can be exported from one RF installation to another (YAML format).
Import Registry Definition File	Enabling another RF installation to duplicate a complete Registry (YAML format).
Support for user defined Derived Data Elements	A Derived Data Element with a calculated designation can dynamically generate a value based on the values of other defined Data Elements or data object model.
Access permissions of each data elements can be modified dynamically (at Runtime)	Current roles in RF are admin, curator, clinician, genetic staff, and patient. This is customisable.
Widgets can be assigned dynamically to data element fields	Widgets can be selected dynamically (at runtime). This allows different display components (e.g. Date fields) to be chosen at run time. For instance, a Date Picker presents a calendar widget.
Exposed REST web service	Allows for patient data to be updated/retrieved by any client that can create HTTP requests.
Longitudinal data snapshots	Storage of longitudinal snapshots of data.
Dynamic multiplicity of fields for some form sections	A form section marked as "multiple" allows its fields to be dynamically added or removed en block (e.g. a multiple contacts section could list contact name, email, relationship as three fields - by marking the section as multiple the framework adds an add/remove button to the page which allows multiple contacts to be added.
Molecular sequence	HGVS annotations can be captured.

Patients in multiple registries	Within the RDRF, patients can be in one or more registries without the need of duplicating patient information.
One RF = Multiple registries	Multiple registries can be managed in one installation.
IP address restrictions	Within RDRF it is possible to define external IP (Internet Protocol) address to ban or allow user(s) from accessing registries defined within the RF.
User login attempts auditing	Audit trails of all user login attempts.
Questionnaire validation	Moderated workflow for questionnaire submission.
19. Open source and RF Deployment	RF is open source (GNU GPL v3). Centos 6 via creation of RPMs which are uploaded to a YUM Repository. Docker image on docker registry.
User documentation	https://readthedocs.org/projects/rare-disease-registry-framework/
Registry landing page	It is possible to create a customisable landing page for each registry.
Consent	Within RF there are capabilities for multiple levels of patient consent.
Demo available	https://rdrf.ccgapps.com.au/demo/ (username and log in: admin | admin; curator | curator; clinical | clinical; genetic | genetic

Acknowledgements

The authors receive funding from the Australian National Health and Medical Research Council (APP634485, APP1055319), EU FP7 Project (HEALTH.2012.2.1.1-1-C), WA Health through the Office of Population Health Genomics, Wellcome Trust Pathfinder Award. The authors wish to acknowledge their involvement in the International Rare Disease Research Consortium and Rare Voices Australia.

References

[1] Y.R. Rubinstein, S.C. Groft, R. Bartek, K. Brown, R.A. Christensen, E. Collier, A. Farber, J. Farmer, J.H. Ferguson, C.B. Forrest, N.C. Lockhart, K.R. McCurdy, H. Moore, G.B. Pollen, R. Richesson, V.R. Miller, S. Hull, and J. Vaught, Creating a global rare disease patient registry linked to a rare diseases biorepository database: Rare Disease-HUB (RD-HUB), *Contemporary Clinical Trials*, **31** (2010), 394–404.

[2] M.I. Bellgard, A. Macgregor, F. Janon, A. Harvey, P. O'Leary, A. Hunter, and H. Dawkins, A modular approach to disease registry design: successful adoption of an internet-based rare disease registry, *Human Mutation*, **33** (2012), E2356–66.

[3] Orphanet Report Series, Disease Registries in Europe. January 2013; Available from: http://www.orpha.net/orphacom/cahiers/docs/GB/Registries.pdf.

[4] M. Bellgard, C. Beroud, K. Parkinson, T. Harris, S. Ayme, G. Baynam, T. Weeramanthri, H. Dawkins, and A. Hunter, Dispelling myths about rare disease registry system development, *Source Code for Biology and Medicine*, **8** (2013), 21.

[5] M.I. Bellgard, L. Render, M. Radochonski, and A. Hunter, Second generation registry framework, *Source Code for Biology and Medicine*, **9** (2014), 14.

[6] M.I. Bellgard, M.W. Sleeman, F.D. Guerrero, S. Fletcher, G. Baynam, J. Goldblatt, Y. Rubinstein, C. Bell, S. Groft, R. Barrero, A.H. Bittles, S.D. Wilton, C.E. Mason, and T. Weeramanthri, Rare Disease Research Roadmap: Navigating the bioinformatics and translational challenges for improved patient health outcomes, *Health Policy and Technology*, **3** (2014), 325–335.

[7] D.B. Reuben and M.E. Tinetti, Goal-oriented patient care-an alternative health outcomes paradigm, *New England Journal of Medicine*, **366** (2012), 777–779.

[8] S.A. Webb, E. Litton, K.L. Barned, and T.M. Crozier, Treatment goals: health care improvement through setting and measuring patient-centred outcomes, *Critical Care and Resuscitation*, **15** (2013), 143–146.
[9] T. Graedon, Is Larry Weed Right?, *Journal of Participatory Medicine*, **5** (2013), e13.
[10] S.T. Grinnon, K. Miller, J.R. Marler, Y. Lu, A. Stout, J. Odenkirchen, and S. Kunitz, National Institute of Neurological Disorders and Stroke Common Data Element Project - approach and methods, *Clinical Trials*, **9** (2012), 322–329.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-15

The HealthierU Portal for Supporting Behaviour Change and Diet Programs

Shlomo BERKOVSKY [a,1], Gilly HENDRIE [b], Jill FREYNE [a], Manny NOAKES [a] and Kathy USIC [c]
[a] *CSIRO Digital Productivity Flagship, Australia*
[b] *CSIRO Food and Nutrition Flagship, Australia*
[c] *Glycemic Index Foundation, Australia*

Abstract. The use of online technologies for supporting participants of behaviour change and diet program is a timely and important research direction. We present HealthierU, adaptive online portal offering a suite of interactive support tools. The portal was evaluated in a 24-week study, which shows that regular reminders trigger increased interaction with the portal. We also analyse interaction patters conducive to weight loss and discuss possible factors of the attrition rates observed in the study.

Keywords. Diet program, online support, usage logs, data analysis

Introduction

With close to 2 Billion adults worldwide classified as obese[2], health professionals investigate the use of information technologies and social support to motivate people to adopt a healthier lifestyle [1]. Weight loss systems have progressed from manual food recording to intelligent systems, in which informative content and interactive services persuade people to change their behaviour [8]. Many people, however, may lack the knowledge and skills required to effectively change their lifestyles.

To address this, we have developed HealthierU, an online portal for supporting people on behaviour change and diet programs, and increasing their engagement with the program. HealthierU is an adaptive portal, underpinned by a high-protein and low-GI diet program [9]. The portal contains several key components: diary, eating and exercise plans, regular reminders, and a suite of tracking tools. In combination, these aim to increase the interaction of the diet participants with the portal and sustain their engagement with the diet program. Hence, HealthierU uniquely offers to diet program participants adaptive support tools and is based on a scientifically validated diet.

This work reports partial results of a 24-week workplace study involving a cohort of employees of a large supermarket chain in a corporate setting. We focus on three metrics of engagement: (i) the overall activity of the HealthierU portal, (ii) the use of the diary by the participants, and (iii) the achieved weight loss. The results show that regular email reminders triggered an increased portal interaction and that sustained

[1] Corresponding Author: PO Box 76, Epping NSW 1710, Australia; E-mail: shlomo.berkovsky@csiro.au.
[2] World Health Organisation, http://www.who.int/mediacentre/factsheets/fs311/en/, accessed May-2015.

engagement of the participants was found to be conducive to their weight loss. We also discuss the factors of the observed levels of engagement and participant attrition.

1. Related Work

Online delivery of diet and lifestyle programs allows interactivity, anonymysation, and personalisation of the program [2], and facilitates tracking and social support tools that may assist lifestyle changes [1]. The online environment presents an opportunity to widely reach, engage, support, and educate participants towards a healthier behaviour.

However, online delivery of lifestyle programs have so far had mixed success. Neve *et al*. concluded that it was not possible to determine the effectiveness of an online intervention in achieving weight loss due to heterogeneity of designs [8]. Wieland *et al*. showed that, compared to offline interventions, digital interventions offered an effective means for weight loss and maintenance [10]. Digital interventions were found to lead to greater weight loss than offline interventions, but to lower weight loss than in-person treatment. The work of Brindal *et al*. on an online weight loss program with no face-to-face interaction showed a moderate weight loss [2]. Although the observed attrition was high, the reach of the program was very broad, counting more than 8,000 participants.

Workplace programs promoting healthy eating have also been evaluated. A review by Mhurchu *et al*. suggested that workplace health promotion programs were associated with moderate improvement in dietary intake [7]. Others have reported limited to moderate evidence for positive effects of nutrition interventions at the workplace [6]. Participation in workplace programs can be a major barrier to the program external validity. For example, a program may be effective in changing lifestyle behaviours for those that participate – but if the observed participation is low then the utility of the program in other settings would be low too [3].

2. The HealthierU Portal

HealthierU was conceived as a lifestyle and behaviour change portal for workplaces, which combines a diet intervention program content with online support tools. The portal provides to the participants a suite of resources aimed at sustaining their engagement with the program and supporting them in a long-term lifestyle change journey.

The underlying diet was a higher-protein and low-GI eating program, associated with greater weight loss and maintenance when delivered in a face-to-face setting [5]. The diet eating plan was based on core food groups as per the dietary guidelines of [9], with stronger emphasis on healthier low-GI carbohydrate foods. The program could be customised for weight loss whereby protein foods are retained, but energy restriction was achieved by reducing carbohydrate and discretionary foods [11]. The workplace implementation of the program offered an opportune environment to reach a large number of people – mainly in sedentary office work– having access to the online portal.

All the participants were provided with a tailored diet plan adjusted to their BMI and weight loss goals. This program was delivered completely online and included the following components and interaction modes:

Static program content. Overview of the higher-protein and low-GI diet program, nutrition tips, meal recipes and exercise instructions, tutorials on the food groups, related articles, and video clips about the use of the portal.

Tailored eating plan (Figure 1-left). Diet compliant menu plan with recipes adapted to the participant's BMI, food intake level, physical activity, and weight loss goals. The plans could have been adjusted to the participant's individual preferences and restrictions, e.g., vegetarian or allergies.

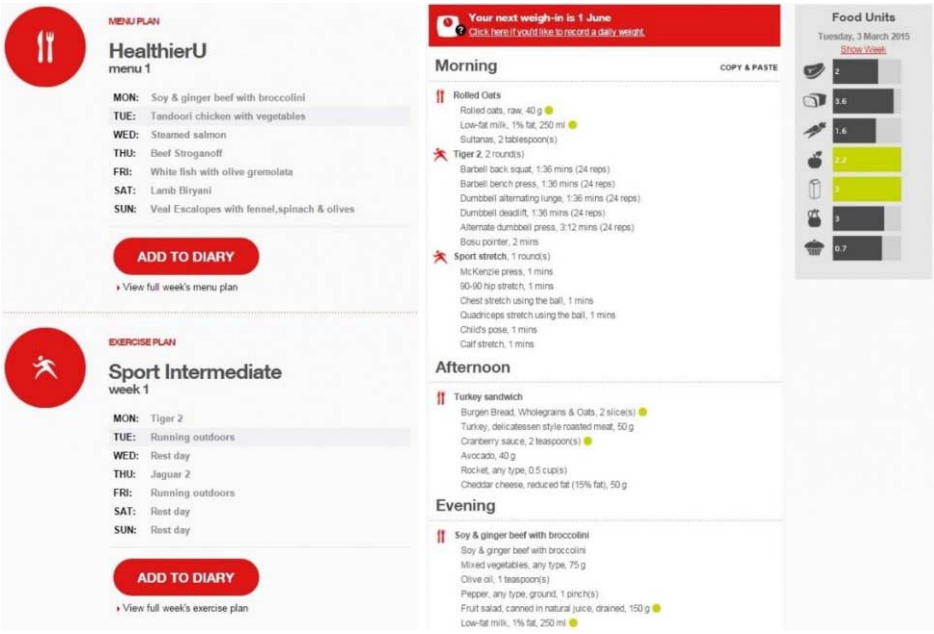

Figure 1. HealthierU screens: (left) weekly food and exercise plan, (right) one day in the dairy.

- Weekly messages. The participants received weekly emails, conveying relevant program information and encouraging them to interact with the portal.
- Personal diary (Figure 1-right). Food and exercise tracker as an electronic diary. The diary allows the participants to plan their meals and exercises, and to report on the food consumed and activity performed. The diary was conceived to be the primary self-monitoring tool of the portal.
- Weight tracker. Weight recording and tracking tool asking for a weekly weight input and visualising the progress towards the weight target.
- Personal results. A suite of interactive tools that allows the participants to view their records, measurements, and progress towards their goals.
- Forum. Online social environment (limited to the program participants) aimed at peer support and increased engagement of the participants.

3. Evaluation

An online study of the Healthier Portal was carried out in 2014. The overarching goal of the study was to evaluate the effectiveness of the HealthierU portal in supporting healthy lifestyle and weight loss. In this work, we focus on three factors: overall portal activity, use of the diary, and weight loss of the participants.

Close to 3,000 employees of a large Australian supermarket chain were invited to participate in the study through direct emails. Out of these, about 1,000 completed the health assessment questionnaire (scores various dimensions of health) and were eligible to participate in the study. The duration of the study was 24 weeks, and it included two cycles of a 12-week diet program. Overall, more than 50,000 actions were logged by the portal over the 24 weeks. We present and analyse a selection of the results.

3.1. Portal Activity

We start with the overall activity of the portal, as quantified by the number of participants logging into the portal. Overall, 655 participants interacted with the portal over the course of the study. As expected, the peak was observed at the first weeks the study, and then the weekly number of unique participants decreased and stabilised at about 50 participants starting from week 7 (Figure 2-left). We observed another activity burst of activity around week 13, when the participants were offered to start the second cycle of the diet. This, however, also stabilised from week 16.

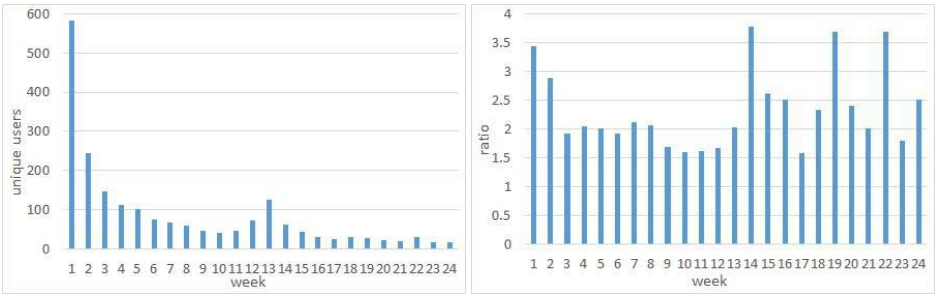

Figure 2. Portal interaction: (left) number of unique participants, (right) ratio between the number of participants on 2 days following email reminders and on other days.

It is interesting to note the role of the weekly emails in triggering the portal activity. For this, we average the number of unique participants seen on Mondays and Tuesdays (the day that the emails were sent out and the following day) and the number of unique participants seen on the other days. The ratio between the averages is shown in Figure 2-right. As can be seen, the number of participants following the Monday emails was consistently greater than on the other days, with the ratio between the two being steadily greater than 1.5 and the average standing at 2.33. This shows that the emails triggered an increased portal activity and brought the participants to the portal.

3.2. Diary Use

As food recording is recognised as one of the factors supporting diet compliance, it is important to analyse the interaction of the participants with the diary. Over the course of the study, the participants created more than 32,000 entries in their diaries. Out of these, 92.5% of entries referred to food intake and 7.5% to physical activity.

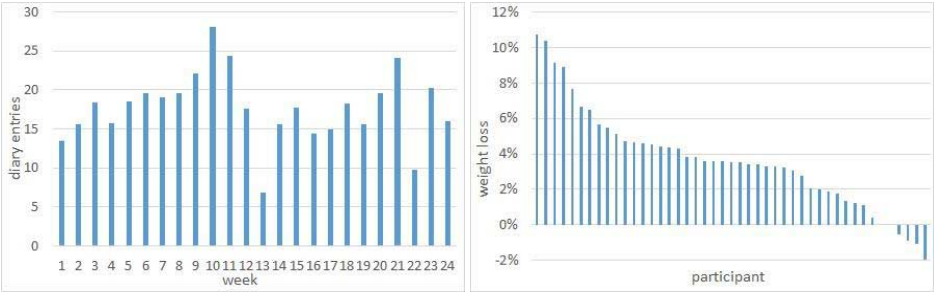

Figure 3. Diary use and weight loss: (left) number of diary entries, (right) relative weight loss.

Looking at the average number of weekly diary entries created by the participants (Figure 3-left), we observe that this hovers between 15 and 25 for most of the weeks. Specifically, in 21 weeks the participants created more than 14 entries, corresponding to average of more than 2 daily entries per participant. The overall average is 17.7 weekly entries per participant. Given that 92.5% of these were food entries, we conclude that the active participants used the diary to plan and record, on average, 2.34 food entries.

3.3. Weight Loss

Finally, we point to the reported weight loss, one of the main metrics of a diet program. In the following analysis, we focus on a group of 45 participants, who reported their weight at least twice, such that the gap between the first and the last report is between 10 and 14 weeks (close to the recommended diet program duration of 12 weeks).

The reported weight loss of these 45 participants ranges from 11.5 kg to -1.8 kg (weight gain). The average weight loss stands at 3.16 kg (SD=2.86 kg), over the average gap of 80.9 days (11.56 weeks) between the first and the last reports. This results in a relative loss of 3.62% (SD=2.86%) of the initial body weight or an average weekly loss of 0.275 kg. The histogram of the relative body weight loss reported by these 45 participants is shown in Figure 3-right.

We further divide the 45 weight loss analysis participants into two groups: those who lost more than the median weight loss of 3 kg (AM group) and those who lost less than that (BM). The former, as expected, reported a higher absolute and relative average weight loss than the latter, 5.21 kg vs 1.12 kg or 5.66% vs 1.53%, respectively, although the gap between the first and the last report was comparable, at 80.7 days vs 81.2 days. See the comparative analysis of the two groups in the left part of Table 1.

Table 1. Above and below median weight loss groups.

	weight loss	*relative weight loss*	*gap between reports*	*weight reports*	*portal actions*	*diary entries*
above median (AM)	5.21 kg	5.66%	80.7 days	13.86	517.05	465.36
below median (BM)	1.12 kg	1.53%	81.2 days	8.05	292.68	264.50

In the right part of Table 1, we analyse the portal activity of the participants in these two groups with regards to several actions. First, we note that the average number of weight reports in the AM group was 13.86, which is substantially higher than the 8.05 reports observed in the BM group (72.3% difference between the two). Second, the average number of portal actions in the AM group was 76.7% higher than in the BM group, 517.05 vs 292.68. Third, the average number of diary entries in the AM group was 465.36, compared to only 264.50 observed in the BM group (75.9% difference). Hence, we conclude that frequent weight reporting, sustained interaction with the portal, and regular food recording are found to be conducive to weight loss.

4. Discussion

This paper presented the HealthierU portal for online support of participants of behaviour change and diet programs. We evaluated the portal in a 24-week study of a higher-protein and low-GI diet program, conducted in a workplace setting. The results showed the effectiveness of weekly emails in triggering portal activity and the role of portal interactions in achieving weight loss. Having said that, the observed participation levels were lower than in earlier studies and, in particular, the attrition was high at the initial stages of the program [2]. This may be attributed to the following factors:

- The participants were encouraged by their employer to take part in the diet program rather than joined the program due to intrinsic motivation to improve their lifestyle. Thus, their motivation was possibly lower than of normal diet program participants, which might have negatively affected their engagement.
- The HealthierU portal was evaluated as part of a workplace program. Hence, the participants inherently had less time to interact with the portal than in their natural environment, e.g., at home. As a result, the observed participation rates were lower and the attrition was higher than expected.
- The forum implementation was not found as appealing and engaging as the state-of-the-art social networks. Also, the forum was not accessible for the first 2 weeks of the program. The highest attrition was observed in this period, whereas afterwards the forum did not reach the desired levels of popularity.
- The HealthierU portal was conceived as a Web-based portal and did not have the complementary mobile interface. This inherently limited its accessibility and could have negatively affected the observed participation rates.

However, we did not conduct post-study interviews with the participants or usability questionnaires to support of refute these conjectures. We intend to address these issues and develop a mobile version of the portal in the future works.

References

[1] Baghaei N, Kimani S, Freyne J, Brindal E, Berkovsky S, Smith G. Engaging families in lifestyle changes through social networking. Int J Human Comp Interact. 27(10):971-990, 2011.

[2] Brindal E, Freyne J, Saunders I, Berkovsky S, Smith G, Noakes M. Features predicting weight loss in overweight or obese participants in a web-based intervention: randomized trial. J Med Internet Res. 14(6):173, 2012.

[3] Bull SS, Gillette C, Glasgow RE, Estabrooks P. Work site health promotion research: To what extent can we generalize the results and what is needed to translate research to practice? Health Educ Behav. 30:537-49, 2003.

[4] Freyne J, Berkovsky S, Smith G. Recipe recommendation: accuracy and reasoning. Proceedings of UMAP. 99-110. 2011.

[5] Larsen TM, Dalskov SM, van Baak M, Jebb SA, Papadaki A, Pfeiffer AF, Martinez JA, Handjieva-Darlenska T, Kunešová M, Pihlsgård M, Stender S, Holst C, Saris WH, Astrup A; Diet, Obesity, and Genes (Diogenes) Project. Diets with high or low protein content and glycemic index for weight-loss maintenance. N Engl J Med. 363(22):2102-13, 2010.

[6] Maes L, Van Cauwenberghe E, Van Lippevelde W, Spittaels H, De Pauw E, Oppert JM, Van Lenthe FJ, Brug J, De Bourdeaudhuij I. Effectiveness of workplace interventions in Europe promoting healthy eating: a systematic review. Eur J Public Health. 22(5):677-83, 2012.

[7] Mhurchu C, Aston LM, Jebb SA. Effects of worksite health promotion interventions on employee diets: a systematic review. BMC Public Health 10:62, 2010.

[8] Neve M, Morgan PJ, Jones PR, Collins CE. Effectiveness of web-based interventions in achieving weight loss and weight loss maintenance in overweight and obese adults: a systematic review with meta-analysis. Obes Rev. 11(4):306-21, 2010.

[9] Noakes M, Clifton P. The CSIRO Total Wellbeing Diet Book 2, Penguin Publ., 2006.

[10] Wieland LS, Falzon L, Sciamanna CN, Trudeau KJ, Brodney S, Schwartz JE, Davidson KW. Interactive computer-based interventions for weight loss or weight maintenance in overweight or obese people. Cochrane Database Syst Rev. 15:8, 2012.

[11] Wycherley TP, Moran LJ, Clifton PM, Noakes M, Brinkworth GD. Effects of energy-restricted high-protein, low-fat compared with standard-protein, low-fat diets: a meta-analysis of randomized controlled trials. Am J Clin Nutr. 96(6):1281-98, 2012.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-22

Decision Support Systems and Line Performance: Case of Gold Coast University Hospital

Martin CONNOR [a], Amir Hossein GHAPANCHI [b,1], Michael BLUMENSTEIN [b], Alireza AMROLLAHI [b] and Mohammadreza NAJAFTORKAMAN [b]
[a] *Centre for Health Innovation, Griffith University*
[b] *School of Information and Communication Technology, Griffith University*

Abstract. Computer-based decision support information systems have been promoted for their potential to improve physician performance and patient outcomes and support clinical decision making. The current case study reported design and implementation of a high-level decision support system (DSS) which facilitated the flow of data from operational level to top managers and leadership level of hospitals. The results shows that development of a DSS improve data connectivity, timing, and responsiveness issues via centralised sourcing and storing of principal health-related information in the hospital. The implementation of the system has resulted in significant enhancements in outpatient waiting times management.

Keywords. Hospital, Health Information Systems, Decision Support System, DSS

Introduction

Use of Information and Communication Technology and Information Systems (IS) have brought various advantages such as cost effectiveness, decreased process time, increased productivity, effective communication, streamlining of processes, access to up-to-date information, and improved globalisation in health sector by revolutionising the collection, recording and manipulation of data [1, 2]. Currently, one of the key differences between high-performing health organisations and those that struggle with performance is their commitment to supporting data management throughout the organisation; ensuring systems are populated with data that is of high quality, very high frequency and with the shortest possible time lag [3].

The development of comprehensive information systems in healthcare practices is essential to effective and efficient health and welfare services. Health Information System (HIS) consists of various approaches, computer hardware, software, and resources to improve the acquisition, retrieval, and use of data in healthcare practices [4-6]. HIS is incorporated with human resource management information systems, laboratory information systems, and hospital patient administration systems. Information systems, mainly at lower stages of the healthcare system (closer to the

[1] Corresponding Author: School of Information and Communication Technology, Griffith University, Gold Coast, Queensland, 4222, Australia. Tel.: +61(7) 5552 8834; E-mail address: a.ghapanchi@griffith.edu.au

collection source), should be clear and sustainable and not overburden health delivery staff or be too expensive to implement [7].

One of the best examples of computer-based information systems is a Decision Support System (DSS) to support organisation's mission, objectives and overall business plan. The main objective of DSS is supporting business or organisational decision-making activities. The Carnegie Institute of Technology conducted a decision-making analysis to collect, organise, and analyse business data in the late 1950s and early 1960s. After that The Massachusetts Institute of Technology (MIT) used computer technology in for a decision-making concept to make data analysis approaches easier [8, 9]. DSS computer-based applications are applied in many diverse fields, including business and business management, healthcare, engineering projects, and education.

DSS facilitates organisational processes in hospitals (other than for diagnosis purposes). For example, an effective decision making application in the planning of healthcare resources was developed to manage levels of demand and patient expectations at the time when budget constraints were enforced on healthcare services in Ireland [10]. The developed application is applied for resource planning and also to measure risks due to emergency department medical staff shortage. In addition McClean and Millard [11] developed DSS tools to improve the efficiency of bed management and facilitate the effective use of resources based on activities within a hospital and its beds.

Effectiveness of using DSS on performance of the organisation has been the subject of attention by researchers in various contexts [12-16]. In the context of the health sector, Forgionne [17] used Analytic Hierarchy Process (AHP) technique to study two sets of factors (process and outcome) to evaluate the effectiveness of DSS in hospitals. However, few qualitative or case studies on the effectiveness of DSS could be found in the context of health sectors. In order to fill this gap, the current paper seeks to study the following research question by conducting a case study:

RQ. How does implementing a DSS in a health service provider organisation improve the efficiency of the service?

This study may provide practitioners in hospitals and other health organisations a better insight into the benefits of DSS and possible challenges as well as lessons learned in a real implementation experience.

1. Research Method

The current research utilises single case study research method. This method has been introduced as facilitators of human knowledge [18] and a tool to help researchers to provide description, test theory, or generate theory [19-24]. In order to conduct this case study we used the general guidelines which are provided by Yin [25]. This includes: identification of a research question, develop study proposition, identify unit of analysis, and develop criteria for interpreting the results.

2. Case Study

The Gold Coast University Hospital (GCUH) opened on 28 September 2013, replacing the Gold Coast Hospital. The $1.76 billion, six-storey facility is more than three times

larger than the Gold Coast Hospital. The new 750-bed medical facility has a complete range of specialties such as surgery, orthopedics, obstetrics, neonatal intensive care, and trauma services. A variety of reporting tools and software are utilised to extract data from numerous clinical information systems / applications to generate activity-related and service performance information. This information is required for differing reporting purposes - including mandatory/legislative commitments, subscription / benchmarking agency arrangements, and activity-related reporting for local Gold Coast Hospital and Health Service (GCHHS) audits.

The capacity to provide responsive analytical information for GCHHS planners and decision makers can be challenging when dealing with an array of disparate clinical information systems that have been purpose-built for particular information needs. Many of these systems have corporately managed business views available, however the connectivity in terms of patient flow and responsiveness across these systems is challenging from a reporting perspective. In particular, the capacity to access regular snapshots of activity to facilitate trend and time series reporting is generally locally manufactured outside of the normal business views (e.g. via separate extracts to a data repository).

Based on this needs a decision support system was fully developed locally in the Queensland context in partnership with the Griffith University Centre for Health Innovation (CHI). The development and implementation of the system was to meet the following objectives: Developing a single GCHHS view of truth, for both corporate and clinical team design elements; Making data meaningful and actionable, optimising its quality, frequency and time-lag by improving the technical capability; Presenting patient and physician level data, in both aggregated and raw format to inform decision making both at an Executive level and the clinical/operational level; and Design, implement and release a series of web based interfaces that help clinicians and HHS management monitor trends of priority KPIs (those designed by clinical teams, Endoscopy, Outpatient flow).

3. Results

The first ‘design principle’ for the new approach to information was agreed to be the goal to produce a ‘single view of the truth’. It is only through taking this approach that integrates data at these various levels that the proper force could be targeted to control the treatment and care systems in the right way. An example of this is the level of transparency with which the board and senior management team can connect a failure to deliver a core dashboard target with its operational cause. If we only see aggregated data at the dashboard level, it is usually presented in a way that is not directly meaningful as to where the problem lies – for example, “we are red on E7 because only 93% of our category one patients treated in June were seen within 30 days”. But drilling down through an integrated information system that is connected to the patient level data, allows quick access to see that the problem was (for example) with 30 patients, 21 of whom were category 1 unbooked waiting for over 7 days in urology which is shown in Figure 1.

The ability to see that urology is the problem each month, allows for the pressure to resolve the particular operational issues to be accurately focused. And from the ‘bottom up’ perspective, this level of transparency is both supportive (since problems are not left to drift), and galvanising – since the operational cause can be seen in terms

of the individual patients who are suffering the delay. In other words, the task becomes described not in terms of 'we have to sort out urology' but rather 'we need to develop and deliver effective care plans for these 21 patients'.

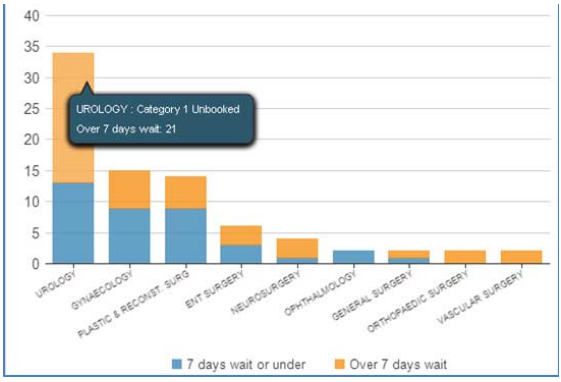

Figure 1. Category 1 Patients Waitlist by Specialty Screenshot.

High frequency data has two further benefits that are fundamental to performance improvement. First, they enable the development of models and charts that can become leading indicators of future performance. We can give a simple example of how we can create a leading indicator as follows. If we can draw up a primary targeting list (PTL) for (say) all Category 2 patients to be treated by Dr Smith by the end of August and we can monitor PTL reductions each week then this will be a reliable leading indicator of Dr Smith's contribution to our Cat 2 E8 target for the end of August (i.e. if the PTL is cleared, there will be no breaches of the time target). If we can then draw up PTLs for all our doctors and monitor this at HHS level, we can build a reliable leading indicator of the whole organisation's performance. This can be seen in Figure 2.

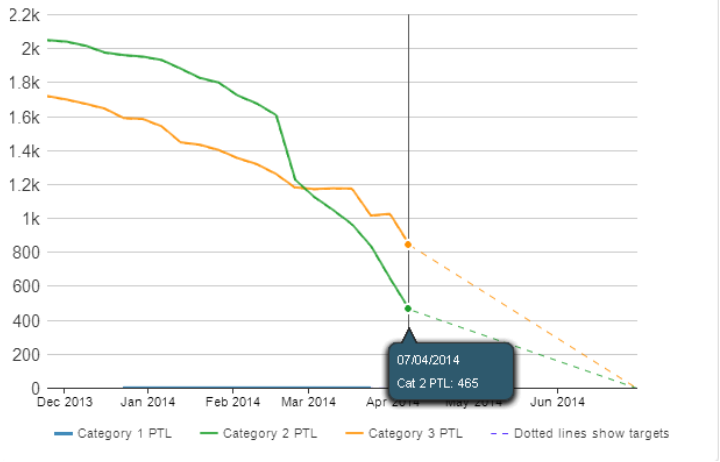

Figure 2. Outpatients PTL Summary All Categories.

In short, the effective establishment of patient level high frequency information systems is a necessary prerequisite to building a learning organisation, and to giving the clinical and management teams tasked with improving performance, the most important tools to do the job. As an example of the results that have been achieved within the GCHHS the below graph (Figure 3) shows an 86% reduction in patients (all categories) waiting across all specialties (9156 in January 2014 to 1244 in November 2014).

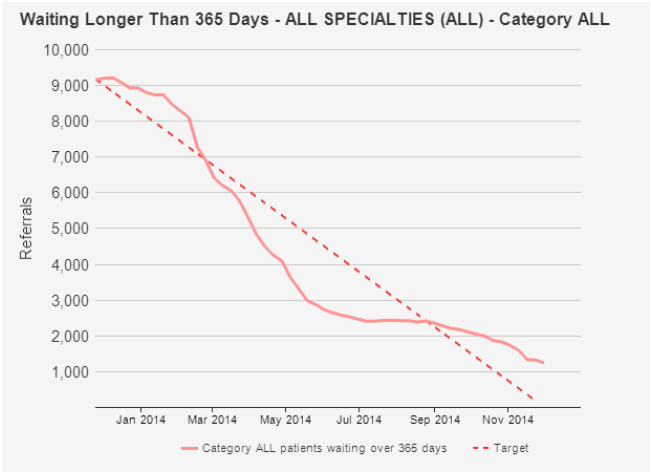

Figure 3. All Category Patients Waiting Over 12 months for All Specialties from January 2014 – November 2014 Screenshot.

4. Discussion and Conclusion

This study evaluated implemented a high-level decision support system which facilitated the flow of data from operational level to top managers and leadership level of GCHHS. According to our results, the development of a DSS helped to resolve the data connectivity, timing, and responsiveness issues faced at the Gold Coast HHS via the centralised sourcing and storing of core health information data (the Data Management element). The system proposed a consolidated view that incorporates high level summary information for executive/managerial visibility, as well as the relevant patient-level information that supports clinical and operational decision making. This system complements the existing business views to ensure the numerous reporting commitments are maintained. The "patient centric" view about the processes helped the system to better reflect the challenges inside the hospital and help the managers to decide efficiently about ways to tackle them. Furthermore, the following objectives were delivered in stages, prioritised on the basis of opportunity and of Tiers of KPIs.

- Develop a single GCHHS view of truth, for both corporate and clinical team design elements.
- Making data meaningful and actionable, optimising its quality, frequency and time-lag by improving the technical capability.

- Presenting patient and physician level data, in both aggregated and raw format to inform decision making both at an Executive level and the clinical/operational level.
- Design, implement and release a series of web based interfaces that help clinicians and HHS management monitor trends of priority KPIs (those designed by clinical teams, CASH, NEAT, NEST, Endoscopy, Outpatient flow).The implementation of the system has resulted in significant improvements in outpatient waiting times management.

References

[1] Najaftorkaman, M., et al., *Recent Research Areas and Grand Challenges in Electronic Medical Record: A Literature Survey Approach.* The International Technology Management Review, 2013. **3**(1): p. 12-21.

[2] Vichitvanichphong, S., et al. Analysis of Research in Adoption of Assistive Technologies for Aged Care. in Proceedings of the 24th Australasian Conference on Information Systems 2013. 2013. RMIT University.

[3] Winter, A., et al., 3LGM2-Modelling to Support Management of Health Information Systems. Studies in health technology and informatics, 2005. **116**: p. 491-496.

[4] Haux, R., Health information systems–past, present, future. International Journal of Medical Informatics, 2006. **75**(3): p. 268-281.

[5] Najaftorkaman, M., et al., A taxonomy of antecedents to user adoption of health information systems: A synthesis of thirty years of research. Journal of the Association for Information Science and Technology, 2014.

[6] Ghanbarzadeh, R., et al., A Decade of Research on the Use of Three-Dimensional Virtual Worlds in Health Care: A Systematic Literature Review. Journal of medical Internet research, 2014. **16**(2).

[7] Ammenwerth, E., et al., Evaluation of health information systems—problems and challenges. International journal of medical informatics, 2003. **71**(2): p. 125-135.

[8] Bakkalbasi, O., et al., Decision support system for the management of an agile supply chain, 1999, Google Patents.

[9] Achabal, D.D., et al., A decision support system for vendor managed inventory. Journal of retailing, 2000. **76**(4): p. 430-454.

[10] Ismail, K., M. Thorwarth, and A. Arisha, Integrated decision support systems for improving emergency department performance in Irish hospitals. International Journal of Operational Research, 2014. **19**(1): p. 40-59.

[11] McClean, S. and P.H. Millard, A decision support system for bed-occupancy management and planning hospitals. Mathematical Medicine and Biology, 1995. **12**(3-4): p. 249-257.

[12] Lilien, G.L., et al., DSS effectiveness in marketing resource allocation decisions: reality vs. perception. Information Systems Research, 2004. **15**(3): p. 216-235.

[13] Ben-Zvi, T., Measuring the perceived effectiveness of decision support systems and their impact on performance. Decision Support Systems, 2012. **54**(1): p. 248-256.

[14] Chan, S.H., The roles of user motivation to perform a task and decision support system (DSS) effectiveness and efficiency in DSS use. Computers in Human Behavior, 2009. **25**(1): p. 217-228.

[15] Ghapanchi, A.H., Wohlin, C., Aurum, A. (2014). Resources Contributing to Gaining Competitive Advantage for Open Source Software Projects: An Application of Resource-Based Theory, International Journal of Project Management, Vol. 32, No. 1, pp. 139-152.

[16] Amrollahi, A., A.H. Ghapanchi, and A. Talaei-Khoei, A systematic literature review on strategic information systems planning: Insights from the past decade. Pacific Asia Journal of the Association for Information Systems, 2013. **5**(2): p. 4.

[17] Forgionne, G., An AHP model of DSS effectiveness. European Journal of Information Systems, 1999. **8**(2): p. 95-106.

[18] Flyvbjerg, B., Five misunderstandings about case-study research. Qualitative inquiry, 2006. **12**(2): p. 219-245.

[19] Eisenhardt, K.M., Building theories from case study research. Academy of management review, 1989. **14**(4): p. 532-550.

[20] Benbasat, I., D.K. Goldstein, and M. Mead, The case research strategy in studies of information systems. MIS Quarterly, 1987: p. 369-386.

[21] Ghapanchi, A.H. and A. Aurum, Competency rallying in electronic markets: Implications for open source project success. Electronic Markets, 2012. **22**(2): p. 117-127.
[22] Ghapanchi, A.H., A. Aurum, and F. Daneshgar, The Impact of Process Effectiveness on User Interest in Contributing to the Open Source Software Projects. Journal of software, 2012. **7**(1): p. 212-219.
[23] Zarei, B. and A. Ghapanchi, *Guidelines for government-to-government initiative architecture in developing countries.* International Journal of Information Management, 2008. **28**(4): p. 277-284.
[24] *Ghapanchi, A.H., and Aurum,, A. (2011). The Impact of Project Licence and Operating System on the Effectiveness of the Defect-Fixing Process in Open Source Software Projects, International Journal of Business Information Systems, Vol. 8, No. 4, pp. 413-424.*
[25] Yin, R.K., *Case study research: Design and methods*2014: Sage publications.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-29

Considering Governance for Patient Access to E-Medical Records

Karen DAY and Susan WELLS
The University of Auckland, New Zealand

Abstract. People having access to their medical records could have a transformative improvement effect on healthcare delivery and use. Our research aimed to explore the concerns and attitudes of giving people electronic access to their medical records through patient portals. We conducted 28 semi-structured interviews with 30 people, asking questions about portal design, organisational implications and governance. We report the findings of the governance considerations raised during the interviews. These revealed that (1) there is uncertainty about the possible design and extent of giving people access to their medical records to view/use, (2) existing policies about patient authentication, proxy, and privacy require modification, and (3) existing governance structures and functions require further examination and adjustment. Future research should include more input from patients and health informaticians.

Keywords. Governance, PHR, portal, policy, medico-legal record

Introduction

People gaining access to and using the content of their own medical records is occurring all over the world in different ways. The vision of New Zealand's National Health IT Plan (NHITP) is to give "New Zealanders and the health professionals caring for them … electronic access to a core set of personal health information" [1]. New Zealand (NZ) is well positioned to give people access to their medical records because of the almost complete uptake of electronic medical record systems in primary care [2]. This access could be in the form of a portal or personal health record (PHR), which is defined as an "… electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorised, in a private, secure, and confidential environment." [3]

To give people access to their medical records safely and productively requires governance, policy, strategy, sound software and process design, business reorganisation and funding infrastructure changes. The WHO defines governance for health as "the attempts of governments and other actors to steer communities, whole countries or even groups of countries in the pursuit of health as integral to well-being" [4]. Governance structures, policies and leadership are required for the successful implementation of the NHITP vision.

Our broader research project aimed to examine concerns and attitudes towards giving people access to and use of their medical records, with particular reference to the design of a portal/PHR, the organisational implications and governance. The purpose of this paper is to report on the findings of the governance interview discussions.

1. Methods

The overall research question aimed to explore the concerns and attitudes of different stakeholders regarding patients accessing and using their medical records for personal care purposes. The overall research design consisted of a survey of GPs and patients who attended their clinics, plus a set of interviews with stakeholders (as described in Table 1). We aimed to conduct up to 25 key informant interviews either face-to-face or via Skype/telephone. The authors divided the interview list and invited stakeholders to participate. The interviews were digitally recorded and a transcribing service developed verbatim manuscripts. This study was approved by The University of Auckland Human Participants Ethics Committee, reference 2013/9417.

The interview schedule was based on our prior research [5-8], literature review and expert opinion. The interviews covered topics in three broad themes:

1. Accessing the record – which data, invitation process to access and by whom, privacy, security, proxy access, barriers to access
2. PHR content, functions and patients' engagement in design and use
3. Organisational issues – work process redesign, workload and governance.

The interviews were digitally recorded and then transcribed. They were analysed line by line in AtlasTi (ATLAS.ti GmbH, Berlin, Germany), and the key concepts were sorted into categories, using a general inductive approach [9]. Categories were grouped into emergent themes and relationships after iterative reading and discussion.

2. Results

We conducted 28 interviews with 30 key informants (two interviews with two informants together) lasting between 30 and 50 minutes. Informants were located across both North and South Islands of New Zealand.

Table 1. Role or constituency of interviewees.

Role/Constituency	Number of interviewees with role/constituency
Patient advocacy or consumer representative role for Health IT	5
GP clinical practice	7 (2 early adopters of portals)
DHB clinical practice	2
PHO, DHB, or professional Collegial role	12
Development of Advisory for Health IT policy	7
Evaluation of Health IT policy	5
Implementation of clinical data sharing Health IT projects	6

Table 1 summarises the roles or constituencies of the interviewees. Many interviewees had more than one role, e.g., seven interviewees were working clinically and had other roles in regional healthcare organisations or with a professional college. The interviewees assumed that the context of patients gaining access to their medical

records was in primary care, via the GP's records, which are almost always electronic. Themes associated with governance are reported in this paper. PHR design, content and functions were explored, but uncertainty about the governance of these features was strong. There was concern about governance of identity authentication, privacy and security of patient access to records. A new take on governance structure, scope and functions emerged in the interviews.

2.1. Uncertainty About the Nature and Design of the Patient View/Use of Medical Records

Although participants all agreed that patients had a right to see their medical record, there were differing views on what, how much and how people would access their records electronically. In principle, most interviewees proposed that over the course of time comprehensive access to all medical records may be desirable, with some caveats in the interest of patient safety, e.g. certain mental health issues. Most assumed that general practice medical records would be the primary source of PHRs. There was consensus that the rollout of functionality and features and degrees of access in this domain should be slow. Some participants reflected on the status quo of sharing the medico-legal record, what policies should be extended, and how this could be influenced by patients accessing their own records. One participant pointed out that the nature of data sharing would not change, saying *"…we're changing the way in which we share the information, not what we're sharing or the safeguards we put around it necessarily"*.

Furthermore, some participants indicated that not enough is known about patient portals and that we are still exploring the nature and scope of what is possible, appropriate or relevant.

2.2. Identity Authentication, Proxy and Privacy

Having established that aspects/whole of the medico-legal record of care are being made available to patients, participants considered how existing policy may need to be adapted. Authenticating a person who needs a logon may need new rules over and above the usual identity management of authenticating patients when they join a primary care practice. They called for guiding principles and protocols, citing the College of GPs or Primary Healthcare Organisations as a responsible body for this role.

> *"As individual clinicians we don't have the networks or the time or the skill to develop that well and we want to be developing consistency so we need those professional groups to really guide us in that area."*

Once the patient has been given logon details, the only way to authenticate a message author is by the virtual profile associated with their logon. Existing privacy and security rules for providers, e.g. the Health Information Privacy Code [10], should be extended to include patients and their proxies. Patient and proxy access is not covered by this code. Proxy access was explored with particular reference to who qualifies. Examples were cited of teenagers who can legally exclude parents from their healthcare, e.g. for family planning consultations with a GP. These examples were extended to a discussion of the implications of being excluded from proxy access to the

medical record by parents/guardians. Another form of proxy is encapsulated in the power of attorney that people give their adult children for the purpose of supporting them in times of incapacity.

> *'...when dad got sick we did it, mum had enduring power of attorney for dad and so we did mum's at the same time so that we didn't have to go back to the solicitor and do it later. But it doesn't mean because I've got that, that I have a right to see her records.'*

Privacy law applies to electronic access in the same way it already applies to existing forms of in-person access. Examples were cited of how privacy could be violated in new ways, and how the responsibility for privacy should remain with the patient or proxy who has authorised access. In other words, it is up to the person who is viewing the record to do so in a private place and not where they are made vulnerable, e.g. a woman in a violent relationship viewing her record where her spouse can see its contents. Furthermore, some interviewees reflected on privacy breaches that had already occurred in public hospitals in NZ and the implications for portals.

> *"We need to set people up for the possibility that it's going to happen and we need to have measures in place to deal with it that are clear and consistent…And that process is going to be transparent and public so that you will know if your data gets leaked you will be told what the outcome is, and there will be an outcome and it won't be a wet bus ticket."*

2.3. New Take On Governance Scope, Structures and Functions

Several existing governance structures were mentioned by different interviewees, who collectively outlined the governance levels, structures and purposes of government, regional and local governance organisations and groups. No participant was clear about the full scope of existing governance structures or how they could be extended to include patients accessing medical records. However, it was agreed that some policy could be extended.

> *"We do have something called the Health Information Security Framework, which tried to resolve issues of security access and privacy. So I think we will layer on top of that the next layer of information governance"*

There was a level of concern about existing governance and national direction, and the lack of portal-specific guidelines for vendors and implementers. National bodies were cited as having important roles, e.g. the National Health IT Board's role in designing, implementing and monitoring the NHITP, and the Board's use of the National Clinical Leadership Group's and Consumer Panel's input in national policy and governance. There was concern that the NHITP needed to be extended in that "*we have got the strategic plan now in terms of, Health IT Plan…but after 2014, 2015 where do we want to go?"* There was a call for the National Health IT Board to *'at least come up with the bones of a standard patient portal."* To compound this, there is

no designated central funding to enable design, development and implementation of a portal, as in the UK and USA.

In contrast, several interviewees were concerned about too much governance at the national level and the need to balance standardisation of a minimum set of capabilities with vendor innovation.

> *"...national level needs to be governance light. What I mean by that is setting some protocols, some principles and models around sanctions that if something does go wrong that there's a sanction model…that works."*

Representation at a national level was commonly raised - a joint collaborative model rather than any one profession and with a strong consumer voice. Some participants pointed out that more patients/consumers are required in governance, while one participant claimed that clinicians were over represented in governance related to patient services. The roles of vocational Councils, e.g. Medical Council, were discussed in terms of the new model of care where patients access their medical records as a matter of course rather than exception.

> *"I think they (Medical council) need to take on board the implications of the electronic record for their membership. And they may require…some sort of accreditation standard by their members that they have competencies to, to manage the electronic health record system"*

When discussing regional governance structures, projects that appeared to have good governance were cited, e.g. the Canterbury shared care record project that had a regional governance and leadership alliance structure.

3. Discussion

Our research explores the concerns and attitudes of giving people electronic access to their medical records. The purpose of this paper is to report on the findings of the governance interview discussions. The NHITP has set the tone for this policy with a vision statement,[1] but application is vague and still under development as an innovation. In contrast to the NHITP approach, the Australian PCEHR is a legal entity enshrined in an Act (Personally Controlled Electronic Health Record Act of 2012) with regulations and rules (http://www.comlaw.gov.au/Series/C2012A00063). The NHITP vision appears to assume that patient portal functionality in existing GP practice management software will be used. NZ patients already have a right to access their clinical notes via a formal in-person process, which can now be extended via an electronic invitation to a patient to begin using their portal. Policies on how to invite patients to use a portal are left up to Primary Healthcare Organisations and District Health Boards. Our findings suggest that clinicians are looking to their registration Councils to develop appropriate policies regarding recourse if adverse events occur.

Governance is required on different levels – top down, bottom up and middle out as described by Coeira [11] - with a light touch leadership from the Ministry of Health and NHITB, and increasing governance responsibilities on regional and local levels respectively. Clinical input is easily obtained, while health informatics and 'social

responsiveness and participation accountability' that represents patients and businesses are often overlooked [12]. A response to concern about the need to extend privacy policy is the development of a guideline by HIGEAG [13]. The emergence of HIGEAG and the relevance of the Consumer Panel, at government level, with less inclusion of patients in regional and local governance, demonstrate that more attention is required on local levels. The Medical Council and other regulatory bodies will be looked to for standard policies, while organisations will need to develop their own policies about patients accessing different types of data, allocating proxy access, and ensuring that patients know how to protect their own privacy [14].

There are limitations to this study. Although we interviewed a significant number of people from a range of perspectives, the interviews covered a lot of ground and therefore only scratched the surface of the implications on governance of people accessing/using their records. This is an exploratory study that has uncovered the need for in-depth examination of the best kind of governance required for safe and productive use of medical records by patients.

In conclusion, appropriate governance that extends what is already being done, to include people about whom medico-legal records are being kept. Structures and policies will require updating to accommodate the extended functions and features of these records, especially in the absence of clear guidelines from the National Health IT Board. Future research should explore the patients' points of view on this topic and the role of health informaticians in governance development and participation.

References

[1] National Health IT Board, *National Health IT Plan. Enabling an integrated healthcare model.* 2010, National Health IT Board: Wellington.

[2] Schoen, C., et al., A survey of primary care doctors in ten countries shows progress in use of health information technology, less in other areas. Health Affairs, 2012. **31**(12): p. 2805 - 2816.

[3] Tang, P.C., et al., *Personal health records: Definitions, benefits and strategies for overcoming barriers to adoption.* Journal of the American Medical Informatics Association, 2006. **13**(2): p. 121 - 126.

[4] Kickbush, I. and D. Gleicher, *Governance for health in the 21st Century*, D. Breuer, Editor. 2012, World Health Organisation: Copenhagen, Denmark.

[5] Wells, S., et al., *Organizational Strategies for Promoting Patient and Provider Uptake of Personal Health Records.* J Am Med Inform Assoc, 2014. Published Online First: 17 October 2014: amiajnl-2014-003055.

[6] Wells, S., et al., *Personal Health records for patients with chronic disease.* Applied Clinical Informatics, 2014. **5**: p. 416-429.

[7] Day, K. and Y. Gu, Influencing factors for adopting Personal Health Records (PHRs), in Health Informatics: Building a Healthcare Future Through Trusted Information - Selected Papers from the 20th Australian National Health Informatics Conference. Studies in Health Technology and Informatics, A.J. Maeder and F.J. Martin-Sanchez, Editors. 2012, IOS Press: Sydney.

[8] Day, K. and Y. Gu, Propensity of people with long-term conditions to use Personal Health Records, in HIC 2013 Health Informatics: Digital Service Delivery - the Future is Now! 2013: Adelaide, Australia.

[9] Thomas, D.R., *A general inductive approach for analysing qualitative evaluation data.* American Journal of Evaluation, 2006. **27**(2): p. 237 - 246.

[10] Office of the Privacy Commissioner. *Health Information Privacy Code*. 2013 [cited 2015 25 May]; Available from: https://www.privacy.org.nz/the-privacy-act-and-codes/codes-of-practice/health-information-privacy-code/.

[11] Coiera, E., *Building a national health IT system from the middle out.* J Am Med Inform Assoc, 2009. **16**(3): p. 271 - 273.

[12] Reti, S.R., H.J. Feldman, and C. Safran, *Governance for personal health records.* Journal of the American Medical Informatics Association, 2009. **16**(1): p. 14 - 17.

[13] National Health IT Board. *Health Information Governance Expert Advisory Group (HIGEAG)*. [cited 2015 12 March]; Available from: http://ithealthboard.health.nz/health-it-groups/health-information-governance-expert-advisory-group-higeag.
[14] Collins, S., et al., Policies for patient access to clnical data via PHRs: current state and recommendations. JAMIA, 2011. **18**: p. i2 - i7.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-36

Designing Technology for Assessments of CALD Patients

Jill FREYNE [a], Courtney POCOCK [b], Dana BRADFORD [a], Karen HARRAP [a] and Sally BRINKMAN [b]
[a] *CSIRO Digital Productivity Flagship, firstname.lastname@csiro.au*
[b] *Speech Pathology Department, Western Health, firstname.lastname@wh.org.au*

Abstract. Interpreters are required to aid communication between clinicians and culturally and linguistically diverse (CALD) patients to ensure appropriate and timely care. Demand for interpreting services however, often exceeds supply. A mobile app to translate clinical assessment questions in 10 common languages using pictorial, written and voice-over prompts to assist patient assessments when interpreters are unavailable has been developed. This paper reports on the User Needs Analysis that informed the app. The analysis consisted of focus groups with allied health clinicians to understand pertinent aspects of initial allied health assessments and the communication needs to be addressed in the design of an app-based patient assessment tool. Outcomes show that of primary importance to clinicians was the ability to not only ask the patients questions, but to communicate information to increase understanding of, and ensure compliance with, treatments and interventions to promote patient function and comfort.

Keywords. Equity, language, mobile, app, digital health

Introduction

The Victorian communities served by Western Health (WH) have some of the highest levels of social-economic and cultural diversity in Australia, with more than 150 different languages spoken. The demand for interpreter services can, at times, exceed supply due to the variable demands for different languages and the availability of a qualified interpreter workforce. The high demand for interpreter services means that culturally and linguistically diverse (CALD) patients are sometimes unable to access timely assessment due to clinicians' inability to communicate directly with a patient, causing inequity in service delivery and frustration and anxiety for patients, carers and staff. Western Health Speech Pathology recognised the impact of delayed assessment of swallowing problems for non-English speaking patients in the absence of an interpreter. Their patients were at increased risk of dehydration, choking and poor quality of life. In response, the Cultural Key Phrases Tool (CKPT) was developed to address the challenge of timely and effective swallowing assessments with limited interpreter access. The CKPT uses predefined phrases, comprised of questions and instructions, with accompanying images to assist clinicians in conducting initial assessments. Previous versions, limited to Speech Pathology, included a flipchart booklet and prototype mobile application.

In this paper we report on the development of the CKPT app, through a project undertaken at Western Health. The goal of the app is to be able to conduct appropriate

and repeatable patient assessments in a variety of allied health disciplines and health settings with the support of technology. It is hoped that use of the app will reduce delays in initial patient assessments, to enhance the patient experience and improve patient care on a system-wide scale. We report here on the User Needs analysis, which included participants from physiotherapy, occupational therapy, dietetics, speech pathology and podiatry, and present the resulting iOS app.

1. User Needs Analysis

As the use of technology increases across hospital systems, mobile and tablet technologies will become the natural home for patient records, assessment tools and patient communication [1]. Mobile tools have been shown to play a role in assisting communication with a diverse range of patients including deaf and autistic patients [2,3,4]. The vision for this project is to develop a tool that allows a clinician to communicate with patients from non-English speaking backgrounds. The app would allow a clinician to select from key phrases that are included in a variety of languages, and through appropriate audio and video files, complete patient assessments and inform care. The intention of the tool is not that it replaces interpreters, but that it is used to ascertain relevant information from the patient until an interpreter can be present.

Scoping the requirements and challenges associated with the creation of the tool was carried out in the form of a User Needs Analysis. During the analysis we worked with staff to promote the idea of a mobile tool to assist in initial patient assessments, and sought input on the achievable assessment goals, supporting app functionality and app content including phrases, questions, images, video etc.

1.1. Methodology

Five allied health disciplines were identified as being potentially suitable for inclusion in this project; physiotherapy; occupational therapy; speechpathology; dietetics; podiatry. Allied Health disciplines were deemed suitable due to the structured format of typical assessments and their use of closed questioning. The allied health focus groups brought together 19 allied health clinicians with the research team. Recruitment of focus group participants was achieved through the managers of each allied health discipline. Five 90-minute discipline based focus groups were conducted. Each focus group was audio recorded and analysed.

1.2. Outcomes

After the initial briefing, focus group participants were enthusiastic about the project and the intended tool. They were highly accepting of a design process that factors in their needs. We present the needs analysis outcomes under the themes of the health assessment goals, app content and finally app functionality.

1.2.1. Health Assessments Goals

Given that the purpose of the app is to support clinicians to conduct their assessments, it was important to understand their processes. Focus group participants were therefore asked to describe the assessments that they typically conduct in the inpatient setting.

Physiotherapy assessments focus on a patient's mobility both prior to admission and currently. Mobility prior to admission is assessed through detailed open-ended questions. Current mobility is assessed through the observation of patients walking, and doing other assessment tasks, such as getting out of bed or climbing stairs. Physiotherapy also often assesses respiratory function. This includes assessment of respiratory rate, chest expansion, oxygen saturation and chest auscultation. Assessments are carried out at the bedside with the clinician seated at the bedhead.

Occupational Therapy assessments are highly structured and detailed. Occupational Therapy assessments gather detailed information on the patient's ability to carry out activities of daily living (ADL) such as cooking and tending to personal hygiene. Occupational Therapy assessments ascertain details pertaining to a patient's home and their cognitive ability.

Speech Pathology assessments focus on a patient's ability to swallow and/or communicate. Speech Pathology assessments traditionally take an open question format. Swallowing assessments determine if it is safe for the patient to eat and drink and require the patient to complete tasks, such as coughing or swallowing. Outcomes of a swallowing assessment inform strategies and the use of texture modified food and fluids. Outcomes of a communication assessment determine communication strategies that should be used when communicating with the patient.

Dietetic assessments cover a wide variety of diagnosis types. In the acute setting, a patient would be referred for a dietetic assessment if they had recently lost a significant amount of weight. Dieticians gather information on past and current weight and eating habits, reasons for weight loss and duration of weight loss. A nutritional assessment is completed requiring significant detail of dietary habits.

Podiatrists typically see patients with foot wounds, and/or patients who are diabetic. The setting for podiatry assessments differs from other disciplines as podiatrists typically spend time at the foot of the bed examining or treating the patient's foot or feet, as well as at the head of the bed talking to the patient. A podiatry assessment often includes treatment (e.g. lancing a wound, debriding), which requires use of instruments such as scalpels. Thus, podiatry clinicians gain verbal consent from patients for podiatry assessments and explain each stage of the podiatry assessment and intervention process as they progress.

The detailed nature of various aspects of the typical assessments described by each allied health group confirmed our view that limited or initial assessments, rather than full assessments, could be conducted through the CKPT app, and that interpreters would indeed be required for a full assessment. In each discipline information that could be used to inform patient care, or strategies for the patient were identified as valuable, and appropriate for inclusion in the app. An initial physiotherapy assessment could focus on *current mobility* using phrases and instructions asking the patient to complete tasks. An initial occupational therapy assessment could ascertain basic *ADL information* by asking questions about help received at home. An initial speech pathology assessment could focus on a *swallowing assessment* to determine if it is safe for the patient to eat and drink. An initial dietetics assessment would ascertain how much *weight* has been lost and the time frame, and the patient preference for supplements. Finally a podiatry assessment could be facilitated if the app informed the patient about the *type of assessment* that would be conducted.

1.2.2. Communicating Strategies

Often when an allied health assessment is completed, the clinician provides the patient with strategies for independent management and education relating to the assessment outcome. Focus group participants from occupational therapy, speech pathology, dietetics and podiatry requested that the CKPT app facilitate communication of strategies to a patient. It was suggested that knowledge of the importance of strategies could increase compliance with recommendations.

Occupational therapy participants noted the value of being able to provide education or strategies to patients around precautions that they should be taking, given their conditions. In addition, the ability to convey information to participants about the hire and/or purchase of equipment was perceived as highly useful in reducing confusion about payments or reluctance to accept equipment. Speech pathology strategies that relate to swallow assessments focus on maximising the swallowing safety of patients. These include the types of food that patients should consume, and the provision of instructions on how to consume food and drinks. Dietetic strategies focus on maximising the potential that supplements will be consumed. Obtaining preference for drink type, communicating that these drinks will arrive, and stressing the importance of their consumption are a desirable functionality of the app. Podiatry strategies include instructions about the use of equipment provided and wound care.

1.2.3. Communication Type

Participants in each allied health area raised the importance of being able to introduce themselves and explain the assessment and its purpose. Similarly, being able to exit an assessment politely and to inform a patient of their likely return is desirable in order to maximise patient comfort and experience.

1.2.4. App Content

Phrases: Four categories of phrases were identified that relate to the flow of a typical assessment. *Introductions*, *Assessment*, *Education* and *Closing*. Participants provided lists of phrases that are desirable to conduct an initial assessment in their clinical area. Suggestions were refined to the minimum number of phrases required for a valuable initial assessment. This resulted in a final library of 116 words and phrases. Suitable answer options and follow up questions were also determined and included.

Media: Focus groups identified the need for video and still images to assist in the comprehensibility of the content of the app for patients, particularly those patients with cognitive or communication impairment. The combination of written words/phrases and audio was also identified to best meet the accessibility needs for patients with hearing or visual impairment. Video demonstrations were requested for instructions or strategies that could not easily be demonstrated by the clinician at the bedside.

Languages: In consultation with the WH Manager of Language Services, occasions where interpreting services were provided were analysed, including instances of unmet need. The languages identified are largely reflective of the common languages identified in the Australian Census (2011) as well as the specific needs of the Hospital. Mandarin, Cantonese, Vietnamese, Italian, Greek, Macedonian, Serbian, Croatian, Arabic and Spanish were selected for inclusion.

1.2.5. App Format and Functions

The basic app functions include the ability to select a language and to select a phrase to communicate to a patient (see Figure 1). With a library of over 100 phrases a sensible grouping of content is required. To this end phrases are listed alphabetically by keyword as well as grouped by discipline (see Figure 2). A third method of navigation requested was a search tool, which allows fast retrieval of individual phrases to potentially increase the applicability of the app beyond the allied health disciplines.

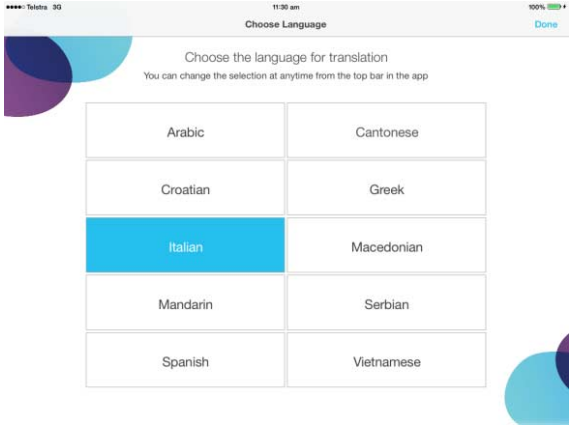

Figure 1. Language Selection.

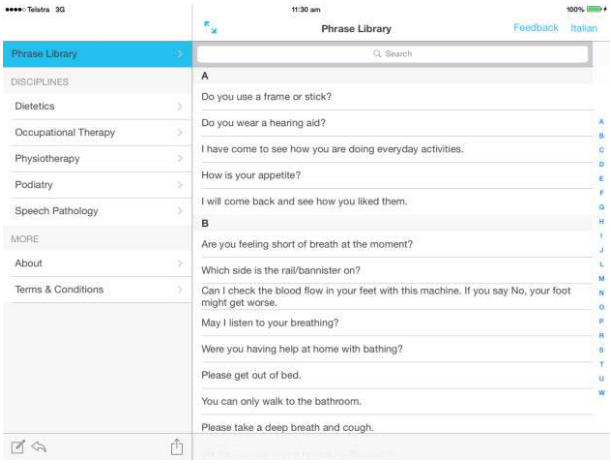

Figure 2. Phrase library and discipline based navigation.

2. CKPT App

The new CKPT App has been designed and developed based on the outcomes of the user needs analysis. The app is simple in design and function. Clinicians select the language that is appropriate for the patient that they wish to assess (see Figure 1). The five allied health disciplines are shown in the left hand panel of Figure 2. Selection of a discipline reveals the assessment structure including Introductions, Assessment etc. (see Figure 3). Expansion of a section such as Assessment reveals the relevant phrases. Selection of an individual phrase reveals the text and media relating to the phrase as appropriate. The display shows the phrase in the language selected in large font, accompanied by smaller English font for the clinician. A menu bar on the horizontal provides access to an audio file of the phrase, answer options and follow up questions.

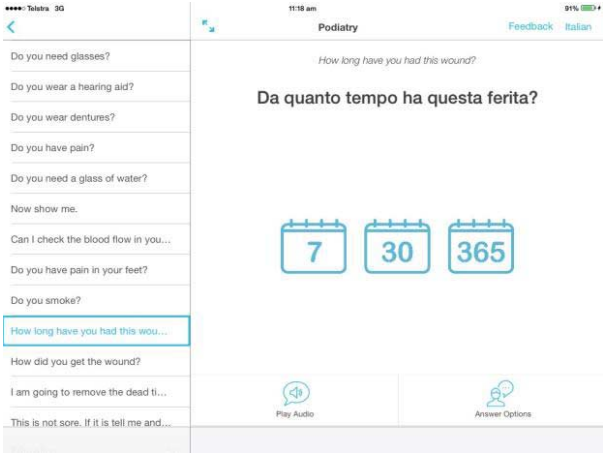

Figure 3. Phrase display.

3. Future Work

A trial of the CKPT app commenced in February 2015 at WH. The evaluation aims to quantify the value in the provision of a mobile tool to assist allied health clinicians in completing initial assessments with patients from a non-English speaking background when an interpreter is not available. The CKPT app has been introduced on five wards and qualitative and quantitative analysis of the impact of the app will be conducted. Specifically we wish to determine impact on wait times for initial assessments and patient and staff acceptance of, and satisfaction with, the CKPT app.

References

[1] Ammenwerth, E., Buchauer, A., Bludau, B., & Haux, R. (2000). Mobile information and communication tools in the hospital. *International journal of medical informatics*, *57*(1), 21-40.

[2] Buttussi, F., Chittaro, L., Carchietti, E., & Coppo, M. (2010). Using mobile devices to support communication between emergency medical responders and deaf people. In *Proceedings of the 12th international conference on Human computer interaction with mobile devices and services,* 7-16, ACM.

[3] Chininthorn, P., et al. (2012). Mobile Communication Tools for a South African Deaf patient in a pharmacy context. In P. Cunningham & M. Cunningham (eds.), Information Society Technologies - Africa (IST-Africa). Dar es Salaam, Tanzania: IIMC International Information Management Corporation

[4] Shane, H. C., Laubscher, E. H., Schlosser, R. W., Flynn, S., Sorce, J. F., & Abramson, J. (2012). Applying technology to visually support language and communication in individuals with autism spectrum disorders. Journal of autism and developmental disorders, 42(6), 1228-1235.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-43

StepKinnection: A Fall Prevention Game Mindfully Designed for the Elderly

Jaime A. GARCIA and Karla FELIX NAVARRO
University of Technology Sydney, FEIT, Sydney, Australia

Abstract. This paper presents the StepKinnection game, a Kinect-driven stepping game for the elderly that delivers stepping exercises to train specific cognitive and physical abilities associated with falls. This system combines a set of suitable age-related features, meaningful exercise routines and an embedded clinical test for fall risk assessment. The combination of these three aspects makes the game potentially useful in practice as the game is appealing to the elderly cohort, trains one of the most important abilities to prevent falls and at the same time allows for a continuous assessment of health outcomes; characteristics not available in the literature nor in current commercial games.

Keywords. Kinect, elderly, fall prevention, stepping game, user-centered design, natural interaction, embedded clinical assessment

Introduction

Falls are the main cause of injury and death in the elderly [1]. Recent studies show that 30% of the population aged 65+ experiences at least one fall every year [2]. In most cases, an individual might suffer numerous physical injuries such as bruises, cuts, sprains, fractures and even a traumatic brain injury. The latter often requires hospitalisation and may result in death for 13% of the cases [3].

Physical activity and structured exercise have been shown to be to most effective strategy to reduce the risk of falling among the elderly [4]. Programs targeting the lower limbs have been demonstrated to improve several dimensions associated with falling such as gait speed and balance coordination [4].

The use of exergames has become a popular approach to engage the elderly in physical activity. A common drive due to the entertainment factor inherent in video games, which increases levels of motivation and enjoyment. However, recent studies have also shown that commercial games, which were originally designed for much younger audiences, might not always be perceived as enjoyable nor beneficial by the aged [5]. One of the main reasons is the usability deficiencies of these games to address the inherent needs of the aged that relates to deteriorations in the human body [6].

In a prior study [7], the authors found a set of hidden usability problems in four commercial balance games which could put an aged player at risk as these games do not accommodate their special needs. For example, a disconnect between what is on the screen and what the user is actually doing, may cause confusion for the player, resulting in feelings of anxiety and frustration while also affecting their balance reflex and mental satisfaction. These findings were crucial to identify key design aspects to suit the needs and preferences of the aged cohort. Later in [8], the authors explored the

use of game technology to reliably perform a clinical test for fall risk assessment. The findings showed that the Kinect [9], an off-the-shelf motion sensing input device, was able to reliably compute a time-based clinical test to assess stepping performance in the elderly.

In this paper, the author now presents a Kinect-based video game that delivers stepping exercises for the elderly. This system explores the combination of: (1) appropriate age-related features; (2) exercise routines aligned to the problem of falling in the elderly; and (3) time-based clinical test that has shown to reliably discriminate between fallers and non-fallers. Characteristics not available in current commercial games.

The remainder of the paper is structured as follows. Section 1 presents a brief summary of related work in the field of games for fall prevention and rehabilitation. In Section 2, the methodology of this study is presented. Section 3 describes the design process and the aspects considered for both clinical assessment and suitability for elder users. Finally, the discussion and conclusions can be found in Sections 4 and 5.

1. Related Work

In the area of fall prevention and safety for the elderly, the use of exergames has shown positive results. An example can be seen in the work done by Kim et al. [10], where the use of a commercial Kinect game showed improvements on hip muscle strength and balance control in older adults after completing an 8-weeks intervention.

In the work done by Yeung et al. [11], a Kinect-based system was used to assess body sway in the elderly. In this system, a person is asked to face a camera-based sensor and stand as still as possible for a certain period of time. Through the collection of spatial data, the amount of displacement in relation to the centre of mass is then calculated and used for diagnosis. Although this system tackles an important risk factor for falling in the elderly, this approach lacks the fun component that engages users to interact with these systems. Uzor et al. [12] developed a series of mini games with the purpose of rehabilitating older adults after experiencing a fall. The main input device used in this system is a pair of inertial sensors that are attached to the player's lower limbs in order to capture leg movements. Each mini game (or task) aims to train a specific function associated with the recovery of muscle strength and power. Exercises range from sit-to-stand and back-to-sit movements, to side steps while holding onto a chair for support. While this system addresses effective strategies to rehabilitate a person after falling, the potential of using the technology to assess the effectiveness of the intervention may not be fully exploited. Although game scores may give a good indication of improvement, these cannot determine progress and the achievement of the expected health outcomes in a reliable manner. In the work done by Schoene et al., [13] a flat dance mat was used to deliver stepping exercises in the form of a dancing game. Its main purpose was to provide a tool to exercise the stepping abilities of older adults. Unlike the commercial game, this version has been adapted to a range of stepping speeds including slow responses. Also, this system allows for the collection of stepping performance data that can potentially predict falls in the elderly. However, while this system trains an important strategy for preventing falls, the mat itself could potentially expose the older person to an increased risk of falling.

In this paper, we describe a Kinect-based video game that delivers stepping exercises for the elderly. This system includes: (1) an appropriate game design

achieved through the use of user-centered design methodologies; (2) three stepping routines that train the ability to take quick reactive steps and avoid obstacles; and (3) a hybrid version of the Choice Stepping Reaction Time (CSRT) task as a clinical assessment instrument [14], a test that has shown to reliably predict falls in older adults.

These aspects make this game potentially useful as an effective tool to reduce the risk of falling in older people as: (1) it was purposely designed for the appeal and needs of the aged cohort; (2) it trains specific physical and cognitive functions associated with falls; and (3) it allows for a continuous assessment of their health outcomes in order to evaluate their progression. None of these characteristics are available in current commercial games.

The following section sets out the methodology used for conceiving this system and the most relevant aspects that were considered through the design process.

2. Building the Game

In order to gather the requirements for the development of this game, a literature review was conducted on the following topics: (1) clinically proven strategies to prevent falls in the elderly; (2) design guidelines for developing entertainment systems for the aged cohort; and (3) validated performance-based tests for falls risk assessment in older people. Based on this review, the following design criteria was developed:

1. The system needs to include appropriate age-related features in order to suit the age-related changes that affect the playability and enjoyment of such games [6]. Also, it should promote a natural interaction as this enhances the operability and engagement with the system.

   Subsequently, the Kinect was selected as the main input device as it facilitates the interaction with the game as no remote controllers are used. This is ideal for the elderly as minimal computer literacy is required. Also, guidelines for developing video games for the elderly where taken into account throughout the design process and several focus groups were conducted to assess the usability of the system.
2. The game should promote physical exercises targeting lower limbs as muscle strength and power are important factors in the risk of falling in the elderly [3]. Exercises should have direct alignment to the specific health outcomes in order to train specific functions associated with the problems of falling in the elderly.

   For that reason, stepping routines with and without a motor inhibition component were incorporated as this ability has been shown to be one of the most effective strategies to prevent a fall from happening [15]. By taking a proactive or reactive step a person can increase their base of support and subsequently regain balance [16].
3. The system should allow the automated identification of health improvements through the incorporation of a clinical test for fall risk assessment [8].

   Then, the Choice Stepping Reaction Time task (CSRT) was selected as a prior study showed that this test it is feasible to measure with the Kinect and is also suitable for translation into a videogame [17]. More importantly, this test has been validated in more detail in older populations including large prospective cohort studies with falls follow-up [18].

3. The StepKinnection Game

The description of the Kinect-based system is described as follows: In this game, the player is an explorer who travels around the globe visiting colorful countries, hunting for treasures and seeking different adventures. Each country presents a challenge where the player gets to experience their traditional music and collect exotic fruits. Completing each challenge takes the player one step closer to winning a trophy. However, the further they travel the more difficult the tasks become. Game play starts with a series of basic levels where players will have the chance to become familiar with the game and coordinate their movements accordingly. Once they have finished these levels, players can move up to more challenging ones related to speed, precision and cognitive complexity.

Figure 1. Short caption Interacting with the Game.

Figure 2. The player collects the fruits by stepping on them.

Figure 3. Training Motor Inhibition.

In order to play the game, the player needs to stand in front of the TV facing the Kinect. Shortly after, the main menu will be presented (Figure 1), where players can select from a list of counties to visit. The player can wave either hand to move the cursor to navigate the menu. Once the level is selected the user moves to the main stepping task.

3.1. Training Stepping

Throughout the game, fruits will appear on the screen every now and then, and the player is expected to collect them. In order to achieve this, the player needs to reach the fruits by stepping on them (Figure 2). As the user moves through the levels, the speed of the appearance and the size of the fruits decrease. This is to encourage players to perform quicker and more accurate steps (i.e., increase in skill) as they advance to higher levels. This task reinforces the ability to take proactive steps that could help an individual to regain balance and avoid falls [19]. Also, as the stepping area decreases, the user needs to be more coordinated to be able to step on the fruits.

3.2. Training Motor Inhibition

In the mid-levels, a lady bug might randomly appear on the screen (Figure 3). Stepping on the lady bug will take two (2) penalty points off their current score reducing their chances of winning. However, if the player remains in position, one (1) point will be awarded.

This motor inhibition task is incorporated with the purpose of adding varied difficulty to the game by slightly increasing its cognitive demand. According to [20], adequate motor inhibition plays an important role in avoiding falls. Training this ability is therefore ideal for situations where avoiding an obstacle can prevent a fall from occurring.

3.3. Training the Ability to Take Quick Reactive Steps

In the higher levels, dollar coins will randomly appear on the screen for a split-second of time. These coins are bonus points that can help players to move faster in the game, with the purpose of encouraging them to step faster. For each dollar coin that they collect, two (2) bonus points will be added to their current score to reward the player. This feature trains the ability to respond quickly to a hazardous situation [19]. This training feature is ideal for circumstances where the person has initiated a step but the environment suddenly changes.

For all the above stepping tasks in the game, the accuracy of the responses is automatically processed by the hybrid clinical test for fall risk assessment that is embedded in the game [8].

4. Discussion

Physiotherapy is moving towards using more portable and practical devices in order to achieve better diagnosis and treatment [21]. The StepKinnection games aims to fill the existing gap in the area of fall prevention through the combination of playful routines, meaningful tasks and the ongoing assessment of health outcomes, aspects that commercial games do not address. A set of stepping exercises available in the literature were found to be easily adapted and translated into this application. Additionally, this game has the potential to provide the physiotherapist with current and historical data of the patient's performance to enable practitioners make informed decisions on the patient's treatment. More importantly, the StepKinnection game has the potential to be used as a cost-effective and portable fall prevention tool that could increase compliance to physical exercises through the fun factor and engagement inherent to video games. Nevertheless, further research is still required to determine whether the system is suitable for clinical practice.

5. Conclusions and Future Work

This paper describes the development of StepKinnection, a Kinect-based video game that delivers a range of step training exercises that aim to prevent the risk of falling in older people. The game-based system builds the Kinect features to allow continuous real time tracking and provisioning of feedback. This is ideal for players with no computer literacy as no game controllers or wearable devices are required to interact with the game. This system not only combines a set of appropriate age-related features with a series of meaningful tasks, but also allows for the collection of clinical data in order to assess progression and the achievement of health outcomes in a reliable manner. This implementation has the potential to be used as a means to provide home-

based therapy with increasing levels of motivation and adherence to physical exercise. The continuation of this work includes the development and integration of a cloud-based system where user's performance information can be stored, automatically analised and accessed remotely. This cloud-based feature aims to help to close the gap between practitioners and patients. The next stage of this study will involve a series of studies in which the feasibility and responsiveness of the system will be evaluated.

References

[1] Kannus, P., J. Parkkari, S. Niemi, and M. Palvanen, *Fall-induced deaths among elderly people.* American journal of public health, 2005. **95**(3): p. 422.

[2] Masud, T. and R.O. Morris, *Epidemiology of falls.* Age and ageing, 2001. **30**(suppl 4): p. 3-7.

[3] Lord, S.R., C. Sherrington, H.B. Menz, and J.C. Close, *Falls in older people: risk factors and strategies for prevention*. 2007: Cambridge University Press.

[4] Gillespie, L.D., M.C. Robertson, W.J. Gillespie, S.E. Lamb, S. Gates, R.G. Cumming, and B.H. Rowe, *Interventions for preventing falls in older people living in the community.* Cochrane Database Syst Rev., 2009(2): p. CD007146.

[5] Neufeldt, C., *Wii play with elderly people.* International Reports in Socio-Informatics, 2009. **6**(3).

[6] Ijsselsteijn, W., H.H. Nap, Y. de Kort, and K. Poels, *Digital game design for elderly users*, in *Proceedings of the 2007 conference on Future Play*. 2007. p. 17-22.

[7] Garcia, J.A., E. Lawrence, K. Felix Navarro, and C. Sax, *Heuristic Evaluation for Interactive Games within Elderly Users*, in *eTELEMED 2011, The Third International Conference on eHealth, Telemedicine, and Social Medicine*. 2011. p. 130-133.

[8] Garcia, J.A., Y. Pisan, C.T. Tan, and K. Felix Navarro, *Step kinnection: a hybrid clinical test for fall risk assessment in older adults*, in *CHI'14 Extended Abstracts on Human Factors in Computing Systems*. 2014, ACM. p. 471-474.

[9] Microsoft. *Kinect for Windows*. 2015; Available from: https://www.microsoft.com/en-us/kinectforwindows/.

[10] Kim, J., J. Son, N. Ko, and B. Yoon, *Unsupervised Virtual Reality-Based Exercise Program Improves Hip Muscle Strength and Balance Control in Older Adults: A Pilot Study.* Archives of physical medicine and rehabilitation, 2013. **94**(5): p. 937-943.

[11] Yeung, L., K.C. Cheng, C. Fong, W.C. Lee, and K.-Y. Tong, *Evaluation of the Microsoft Kinect as a clinical assessment tool of body sway.* Gait Posture, 2014. **40**(4): p. 532-8.

[12] Uzor, S. and L. Baillie, *Exploring & designing tools to enhance falls rehabilitation in the home*, in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2013, ACM. p. 1233-1242.

[13] Schoene, D., S.R. Lord, K. Delbaere, C. Severino, T.A. Davies, and S.T. Smith, *A randomized controlled pilot study of home-based step training in older people using videogame technology.* PloS one, 2013. **8**(3): p. e57734.

[14] Lord, S.R. and R.C. Fitzpatrick, *Choice Stepping Reaction Time: A Composite Measure of Falls Risk in Older People.* Journals of Gerontology Series A: Biological Sciences & Medical Sciences, 2001. **56A**(10): p. M627.

[15] Feldman, F. and S.N. Robinovitch, *Reducing hip fracture risk during sideways falls: evidence in young adults of the protective effects of impact to the hands and stepping.* Journal of biomechanics, 2007. **40**(12): p. 2612-2618.

[16] Maki, B.E. and W.E. McIlroy, *Control of rapid limb movements for balance recovery: age-related changes and implications for fall prevention.* Age and ageing, 2006. **35**(suppl 2): p. ii12-ii18.

[17] Garcia, J.A., K. Felix Navarro, D. Schoene, S.T. Smith, and Y. Pisan, *Exergames for the elderly: Towards an embedded Kinect-based clinical test of falls risk.* Stud Health Technol Inform, 2012. **178**: p. 51-7.

[18] Schoene, D., S.R. Lord, P. Verhoef, and S.T. Smith, *A Novel Video Game-Based Device for Measuring Stepping Performance and Fall Risk in Older People.* Archives of physical medicine and rehabilitation, 2011. **92**(6): p. 947-953.

[19] Pavol, M.J., E.F. Runtz, and Y.-C. Pai, *Young and older adults exhibit proactive and reactive adaptations to repeated slip exposure.* The Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 2004. **59**(5): p. M494-M502.

[20] Potocanac, Z., W. Hoogkamer, F.P. Carpes, M. Pijnappels, S.M. Verschueren, and J. Duysens, *Response inhibition during avoidance of virtual obstacles while walking.* Gait & Posture, 2014. **39**(1): p. 641-644.
[21] *InPractice 2025: Final report*. 2013, Australian Physiotherapy Association.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-50

Le Bon Samaritain: A Community-Based Care Model Supported by Technology

Valerie Gay, Peter Leijdekkers, Asif Gill and Karla Felix Navarro
Faculty of Engineering and Information Technology, University of Technology Sydney
PO Box 123, Broadway 2007, NSW, Australia.
{Valerie.Gay, Peter.Leijdekkers, Asif.G ill, Karla.FelixNavarro}@uts.edu.au

Abstract
Background: The effective care and well-being of a community is a challenging task especially in an emergency situation. Traditional technology-based silos between health and emergency services are challenged by the changing needs of the community that could benefit from integrated health and safety services. Low-cost smart-home automation solutions, wearable devices and Cloud technology make it feasible for communities to interact with each other, and with health and emergency services in a timely manner.
Objectives: This paper proposes a new community-based care model, supported by technology, that aims at reducing healthcare and emergency services costs while allowing community to become resilient in response to health and emergency situations.
Methods: We looked at models of care in different industries and identified the type of technology that can support the suggested new model of care. Two prototypes were developed to validate the adequacy of the technology**.**
Results: The result is a new community-based model of care called '*Le Bon Samaritain*'. It relies on a network of people called '*Bons Samaritains*' willing to help and deal with the basic care and safety aspects of their community. Their role is to make sure that people in their community receive and understand the messages from emergency and health services. The new care model is integrated with existing emergency warning, community and health services.
Conclusion: Le Bon Samaritain model is scalable, community-based and can help people feel safer, less isolated and more integrated in their community. It could be the key to reduce healthcare cost, increase resilience and drive the change for a more integrated emergency and care system.

Keywords. Software, Telemedicine, Connected health, Community-centred care, Wearable devices, Wireless sensors, Age Care Informatics.

Introduction

The effective care and well-being of a community is a challenging task and, in order to reduce costs and make the community more resilient, there is a need to find alternative ways to empower communities and give them more control of their health care and well-being, in particular in emergency situations. Communities would benefit from integrated health and safety services. In addition, low-cost technology makes it feasible for community members to interact with each other, and with health and emergency services in a timely manner.

Today, members of the community can only turn to health and emergency services when something happens in the community. It is a burden on the emergency and

healthcare systems and quite often the community has the capability to support itself and deal with the day-to-day non urgent, non life threatening issues. However there is a need for a new model where the community is more in charge and empowered [1].

With the current model, it is difficult to reach the most isolated people in case of emergency, in particular in remote areas. Emergencies may have financial and welfare impacts on communities and especially on elderly people who quite often live alone and have mobility and health issues [2]. It is important for all the members of the community to receive and understand health and emergency information. Timely emergency information exchange may minimize the adverse impacts on the wellbeing of isolated elderly people [3]. Emergency management agencies provide generic warning information to local communities via formal (e.g. websites, TV, radio) and informal channels (e.g. social networks) [4]. Health services provide generic medical services to ensure the wellbeing of the people impacted by the emergencies. However, such generic warning information and health services need to be personalised to be understood by the different members of the community. In case of emergency, the community, health and emergency services need to collaborate and share their information in an effective manner before, during and after the emergency situation [5].

This paper presents our vision for a new community-based care model called '*Le Bon Samaritain*' that aims at reducing healthcare and emergency services costs while allowing community to become resilient in response to health and emergency situations. A model is developed using a well-known design research approach, which is appropriate for developing and evaluating proposed model [6].

The paper then discusses the technology supporting the new model. It supports the exchange of information between emergency services, health services and local communities using a wide range of wireless technologies including mobile phones. The technology is suitable to handle unpredictable health and disaster situations, as well as, the demand for additional computing resources, which are required to support the real-time personalised information exchange.

1. A new model of care '*Le Bon Samaritain*'

Le Bon Samaritain relies on a network of people, '*Les Bons Samaritains*', willing to help and deal with the basic care and safety aspects of their community. Their role is to make sure that people in their community receive and understand emergency messages coming from the community, emergency and health services.

The *Bon Samaritain* model uses the concept of good samaritan, someone who comes forward to render assistance in an emergency without expectation of being paid. *Bons Samaritains* are volunteers in the local community who are willing to help and they operate as a network (i.e. share responsibilities). They volunteer by joining the Bon Samaritain social network. *Bons Samaritains* are not liable for any damage caused by their well-intentioned acts or omissions. Each Australian state and territory has introduced Good Samaritan legislation. The model adopted in the legislation is reasonably consistent across the jurisdictions, except Queensland. [7]. The Queensland law only provides protection from civil liability for doctors and nurses, and members or employees of listed organisations (such as the volunteer emergency services) [8]

The *Bon Samaritain* volunteers operate in a community where homes are equipped with technology to receive community, health and emergency information and warnings (e.g. epidemics, bushfire warnings). Alarms can be raised by a community

member, automatically by devices and sensors in the house or using a mobile device. Warnings can be displayed or presented using one of the following technologies: TV, radio, mobile phones, smart light bulbs changing color or flashing. The *Bon Samaritain* system is connected to the existing health and emergency services as shown in figure 1.

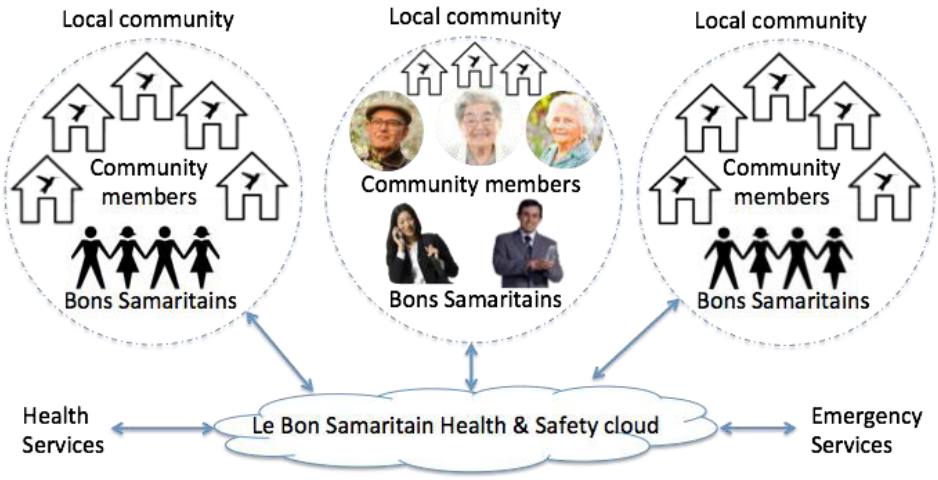

Figure 1. A new model of care combining Health, Emergency and Community services.

In this model, *Bon Samaritans* deal with non urgent, non life threatening alerts raised in their community and therefore save time (and money) by not involving health and emergency services. *Bons Samaritains* do not replace emergency and health services for urgent life threatening alarms and in those cases, the normal procedures and channels of communication are used. For example, a *Bon Samaritain* volunteer will act when a member of the community does not react to an alert (e.g. fire alarm) within reasonable time and the volunteer will then go to the person's residence or phone to check on that person.

We identified 6 alert levels (green - red) inspired by the Triage system commonly used in hospitals [9]. Table 1 shows examples of the various alert levels and interactions between community members, Bon Samaritains and health/emergency services. Using smart home technology, the sensors in a residence can communicate with the Bon Samaritains and emergency/health services if a certain alarm level has been reached.

The model is flexible and can be tailored to a specific community (e.g. rural, urban) and specific needs of that community (e.g. elderly with social isolation problems, fire prone area). The alarm threshold levels in Table 1 are refined in cooperation with the different stakeholders in the community and have to comply with the local regulations. The user gives consent that data collected from sensors will be made available to the Bon Samaritans and emergency/health services for the sole purpose of providing monitoring services. The data is securely stored in the cloud and not accessible by other parties.

Table 1. Examples of Alert levels and interactions

	Green 0 OK	**Lime green 5 Non-urgent**	**Yellow 4 Semi-urgent: not life threatening**	**Amber 3 Urgent: not life threatening**	**Orange 2 Emergency: could become life threatening**	**Red 1 Immediate: life threatening**
Community members ↑↓ *Bons Samaritains*	OK	e.g. Saw something /will do something	e.g.Feeling down Worried /Will pass by at 2pm	e.g.Locked out of house/ will open the door in 3mn	e.g.Kitchen on fire / fire brigade on its way	e.g. Heart attack ambulance called defibrillator on its way called
Community members ↑↓ Health and emergency services	OK	Info to the Community e.g. severe thunderstorm expected	Info to the Community e.g. heavy rain with minor flooding expected	Info to the Community e.g. bushfire 50 kms from community	Two way info e.g. Kitchen on fire	Two ways info e.g. Heart attack
Connected home ↑↓ Community members and *Bons Samaritains*	OK	e.g. battery low of smoke detector	e.g. smoke detector not working	e.g. gas leak detected	e.g. heart rate above 150 bpm for elderly person not moving	e.g. Fall detected, no reaction and heart rate below 50bpm
Connected home ↑↓ Health and emergency services	none	none	none	none	e.g. gas leak detected by sensors no alarm raised by owner	e.g. fire detected no alarm raised by owner within 2mn
Bons Samaritains ↑↓ Health and emergency services	none	none	none	Two way info e.g. potential flooding threatens the community	Two way info e.g. Assistance with person being unwell	Two way info. e.g. person has a heart attack. CPR instructions given

2. Technology to support 'Le Bon Samaritain'

For the realisation of the *Bon Samaritain* care model we use a combination of low cost, off-the-shelf sensors and smart-home components to form a '*connected home*'. The sensors can be inside the house or outside (e.g surveillance camera) and are securely connected to the *Le Bon Samaritain* cloud. Other members of the community are connected to the cloud via their mobile devices or web browser. A member of the community decides what he/she wants to be monitored. The technology used varies from smoke detectors, movement detectors, webcams to wearable devices monitoring someone's vitals signs such as heart rate and respiration. For rural areas, outdoor infrared sensors can be used to detect approaching bushfires or intrusion detection sensors. The role of the *connected home* is to gather, filter and analyse the incoming data and to trigger and manage the alarm events based on the layered alert model depicted in Table 1. More importantly, the *connected home* acts as a social gateway entity that allows the members of the community to interact with each other.

2.1. Bon Samaritain volunteers

The data collected by the sensors, as well as, given by community members (e.g. locked myself out of the house) is aggregated, analysed and then presented to the group of *Bon Samaritains* for that particular community. Figure 2 left shows the dashboard for a *Bon Samaritain* responsible for a group of people. A triage system is used for the different alert levels as described in table 1. In this example, a red alert is generated for John Smith because of prolonged high heart rate. The mobile app will automatically alert all *Bon Samaritains* for that community and the first *Bon Samaritain* to react can then decide to call John or go directly to his apartment to check it out. If the alert is life

threatening and no *Bon Samaritain* reacts within a certain time interval the alert is forwarded to health or emergency services. A yellow alert is generated for less urgent matters such as being locked out of the apartment. The green status indicates that all is okay and no action needs to be taken. When a member of the community is away or disabled monitoring the offline status is shown.

Figure 2. *Bon Samaritain dashboard and alarm raised situation.*

2.2. Bon Samaritain Cloud

The *Bon Samaritain Cloud* is an on-demand cloud service for information exchange. It enables real-time information exchange between the involved parties such the members of a community, emergency and health service agencies. There are three key information components: *local community information*, *emergency warning and health information.* The emergency warning and health information component is enhanced with geolocation and delivers the information to the communities via different channels depending on the situation (e.g. mobile device, TV, radio or smart bulbs). The *Bon Samaritain Cloud* stores and manages information about the community and health and emergency services. It allows the creation of individual community profiles and each community can manage its own community information. People living in a particular area can join a community and configure the sensors and wearable devices they use and how they want to be monitored. The user can opt-in for one or more community services (e.g. emergency only). Users are in control of what they want to expose to the *Bon Samaritain* volunteers. The granularity of the consent depends on the category of service chosen and on the community. Each community receives emergency warning and health information alerts applicable to that community. The *Bon Samaritain Cloud* allows *Bon Samaritain* volunteers and individual members to send alerts to health and emergency services based on the triage system described above.

3. Discussion

The new model of care described in this paper has the potential to empower the community and reduces the burden on health and emergency services. The underlying technology presented is currently under development. Earlier prototypes addressing part of the *Bon Samaritain* solution show that it is feasible to build a low cost, scalable community focused system. In one proof of concept we used a Raspberry-Pi device using 3G network to communicate with the *Bon Samaritain Cloud* (Google App Engine). The device can be installed anywhere in a home and alerts are shown using lights (red, yellow, green) and/or sound for various alert levels. The prototype provided insight in the applicability and viability of inexpensive devices.

With governments wanting to spend less money on health and emergency services and at the same time a growing population where people live longer we believe that the model proposed in this paper has potential. It goes back in time where community care was normal and where people would look after each other. We give community care a new meaning by using off-the-shelf technology and reconnect people using digital technology but not dismissing the human-to-human interaction when needed. The philosophy is that small problems are solved within the community using *Bon Samaritains* and only emergency and health services are used when really needed. This should lower the burden on these agencies, save time and money and empower the communities. This initial study highlights that it is technologically feasible. The new model of care is in line with the Natural Disaster Resilience Program [10] whose focus is to enhance the community resilience to crisis situation for sustainable communities across Australia. It can help people feel safer, less isolated and more integrated in their community.

References

[1] Commonwealth of Australia 2013, National Strategy for Disaster Resilience, Community Engagement Framework, Australian Emergency Management Institute, Commonwealth Attorney-General's Department. http://www.em.gov.au.

[2] W. B. Lee, Y. Wang, W. M. Wang, C.F. Cheung, An unstructured information management system (UIMS) for emergency management, Knowledge Management Research Centre, Department of Industrial and Systems Engineering, The Hong Kong Polytechnic University, 2012.

[3] J. Sutton, and L. Plaen, *Backchannels on the From Lines Emergent uses of social media in the 2007 California Wildfires,* University of Colorado: Bolder, 2011.

[4] Royal Commission Report. *Queensland Floods Commission Inquiry – Interim Report*, 2011, www.floodcommission.qld.gov.au.

[5] J. Fan, P. Zhang, D.D. Yen, G2G information sharing among government agencies*, Information and Management*, 2014, 51, pp. 120-128.

[6] Duffy, A. and O'Donnell F. 1998, 'A Design Research Approach Presented at AID'98 Workshop on Research Methods in AI in Design', Lisbon, Portugal, 19 July 1998, pp 20-27 & Published in "Critical Enthusiasm - Contributions to Design Science", ISBN 82-91917-08-6, Dec'99, pp33-40.

[7] A.Q. Gill and D. Bunker, Crowd Sourcing Challenges Assessment Index for Disaster Management, *Proceedings of the 18th AMCIS 2012*, Seattle, USA.

[8] Civil Law (Wrongs) Act 2002 (ACT) s 5; Civil Liability Act 2002 (NSW) ss 55-58;Personal Injuries (Liabilities and Damages) Act 2003 (NT) s 8; Law Reform Act 1995 (Qld) ss 15 and 16; Civil Liability Act 1936 (SA) s 74; Civil Liability Act 2002 (Tas) ss 35A-35C; Wrongs Act 1958 (Vic) ss 31A-31D; Civil Liability Act 2002 (WA) ss 5AB and 5AD.

[9] Law Reform Act 1995 (Qld) s 16.

[10] Victoria Health, better health channel, Emergency department, http://www.betterhealth.vic.gov.au.

[11] NDRP 2013-15, http://www.mpes.nsw.gov.au/content.php/1269.html.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-56

An Improved Patient-Specific Mortality Risk Prediction in ICU in a Random Forest Classification Framework

Soumya GHOSE [1], Jhimli MITRA [1], Sankalp KHANNA [1] and Jason DOWLING [1]
[1] *Australian e-Health Research Centre, CSIRO, Digital Productivity Flagship.*

Abstract. Dynamic and automatic patient specific prediction of the risk associated with ICU mortality may facilitate timely and appropriate intervention of health professionals in hospitals. In this work, patient information and time series measurements of vital signs and laboratory results from the first 48 hours of ICU stays of 4000 adult patients from a publicly available dataset are used to design and validate a mortality prediction system. An ensemble of decision trees are used to simultaneously predict and associate a risk score against each patient in a k-fold validation framework. Risk assessment prediction accuracy of 87% is achieved with our model and the results show significant improvement over a baseline algorithm of SAPS-I that is commonly used for mortality prediction in ICU. The performance of our model is further compared to other state-of-the-art algorithms evaluated on the same dataset.

Keywords. ICU mortality prediction, random forest

Introduction

An accurate tool for the prediction of risk of mortality for ICU patients will facilitate optimal allocation of staff and resources to high risk patients and ensuring timely interventions. Development of a reliable risk stratification tool in the ICU is however a challenging task. Given the nature of ICU functionality, a complete set of time varying patient readings are not always required and hence are not recorded. Often these variables are not recorded at equal intervals of time. These factors combine together generating missing values in the time series. Developing a reliable prediction system is difficult in such a scenario. In 2012, an academic challenge, Physionet [3], prompted several research attempts to model and predict the risk of inpatient mortality of ICU patients from such time series data related to ICU stays. Five static variables and thirty-seven time series variables (recorded for vital signs) analysed over a period of 48 hours were made available to researchers to build an ICU mortality risk prediction system. The data sets remain freely available as a basis for quantitative comparisons of mortality predictor models.

In this study, the PhysioNet challenge dataset is used to develop a random forest classifier [4] to simultaneously predict and assign a risk value to ICU patients. The

[1] Corresponding author: Soumya Ghose, The Australian e-Health Research Centre, CSIRO, Level 5 - UQ Health Science Building 901/16, Royal Brisbane and Women's Hospital, Herston Qld 4029 Australia; E-mail: Soumya.Ghose@csiro.au

proposed system's performance is compared to the traditional SAPS-I [5] score in prediction of patient mortality. The performance of the proposed model is further compared with selected state-of-the-art algorithms presented in the PhysioNet Challenge. The rest of the paper is structured in the following manner; the random forest classifier is presented in section 2 followed by results and discussions in sections 3 and 4 respectively.

1. Method

The study employed a publicly available dataset [6] released by the PhysioNet challenge for the prediction of in-hospital mortality of ICU patients. The dataset comprised of information related to 4000 ICU stays of adult patients who were admitted to cardiac, medical, surgical and trauma ICUs. Information for each stay included up to 42 variables that were recorded at least once in the first 48 hours after admission. Five of these were general descriptors, age, gender, height, weight and ICU type, assigned at admission and 37 were measurements recorded in chronological order as a time series. Not all measurements were recorded for all patients. Additionally, a SAPS-I [5] score and a label of mortality was assigned to each patient to facilitate model evaluation and comparison to SAPS-I, the chosen benchmark for the competition. Table 1 presents a list of attributes available for analysis and the percentage of patients for whom at least one measurement was available.

Table 1. Time series variables and percentage of patients for whom, at least one measurement was available during the first 48 ICU hours.

Measurements	**%**	**Physical Units**
Blood Pressure - Invasive (diastolic, mean, systolic)	98.4	mmHg
Blood Pressure - Non-invasive (diastolic)	87.3	mmHg
Blood Pressure - Non-invasive (mean)	87.2	mmHg
Blood Pressure - Non-invasive (systolic)	87.6	mmHg
Albumin	40.5	g/dL
Alkaline phosphate	42.4	IU/L
Alkaline transaminase	43.4	IU/L
Aspartate transaminase	43.4	IU/L
Bilirubin	43.4	mg/dL
Blood urea nitrogen	98.4	mg/dL
Cholesterol	7.9	mg/dL
Creatinine	98.4	mg/dL
Fractional inspired oxygen	67.6	[0-1]
Glasgow Coma Score	98.4	[3-15]
Glucose	97.5	mg/dL

Serum bicarbonate	98.2	mmoI/L
Hematocrit	98.4	%
Heart rate	98.4	Bpm
Serum potassium	97.9	mEq/L
Lactate	54.8	mmoI/dL
Serum magnesium	97.5	mmoI/L
Mechanical ventilation	63.1	Yes/no
Serum sodium	98.2	mEq/L
PaCo2	75.4	mmHg
PaO2	75.4	mmHg
pH	75.9	[0-14]
Platelets	98.3	Cells/nL
Respiration rate	27.7	Bpm
SaO2	44.7	%
Temperature	98.4	Celsius
Troponin-I	4.7	Ug/L
Troponin-T	21.9	Ug/L
Urine output	97.4	mL
WBC	98.2	Cells/nL
Weight	67.7	Kg

A primary challenge to build the prediction system was the missing data, as all the static and dynamic attributes for all patients were not available. The missing values were substituted with zeros to facilitate equal temporal sampling of data. Data for every time series was further sampled at every second hour for the entire 48-hour period. This introduces uniformity in sampling of each attribute (Table 1) across all patients. The mean, maximum, minimum values and the standard deviation of each of these intervals within the 48-hour period, for each time series attribute and the static variables were concatenated to create the feature vector for a particular patient.

Random forest was chosen because of its proven capability to perform consistently well with noisy and missing data. A random decision forest is a supervised learning method and is an ensemble of decision trees. A decision tree is a set of two types of nodes, the split nodes and the leaf nodes. In order to train a model, the training feature space is randomly sampled with uniform sampling of the feature thresholds at each split node with the aim of maximising the information gain [4]. Therefore, each split node stores a decision function, while the empirical distribution of the posterior probability $p(y \mid x)$ of assigning label y to the training data x is stored at the leaf nodes, where $x \in \Re^m$ is the feature vector, and $y \in \Re^n$ is the output or prediction variable. In this work, $x_k, k = 1,\ldots,K$ is a subset of the available training samples, each

with the static and time series attribute (as presented in Table 1) scores along with a given label (i.e. death or survival). The aim is to model a predictor that determines the probability for assigning a particular class label given a new data.

To predict the label of a new data x, the feature is pushed down through the learned split functions and once it reaches the leaf node, the stored distribution $p(y \mid x)$ is used to predict the label. The overall prediction of the forest with T decision trees is finally obtained by averaging the individual tree prediction as follows,

$$p_t(y \mid x) = \frac{1}{T} \sum_{t=1}^{T} p_t(y \mid x) \tag{1}$$

Each of the decision trees in a random forest is a weak classifier and an aggregate of their individual predictions is used to obtain a final prediction. A single decision tree is known to suffer from over-fitting [4], while, a random forest offers better generalisation capabilities by randomising the features and feature threshold values at the split nodes. In this work, the number of trees was fixed to 1000 to improve the generalisation capability of the model.

2. Results

The performance of our model was compared to the benchmark SAPS-I score provided in the dataset. A ten-fold cross-validation was employed and common evaluation metrics like the true positive rate (TPR, or Sensitivity), false positive rate (FPR), positive predictive value (PPV), negative predictive value (NPV) and accuracy were computed to evaluate the performance of the classifier. Receiver Operating Characteristic (ROC) curve analysis was employed to measure the performance of the models, with the c-statistic (or AUC), representing the area under the ROC curve, also used as a measure of discrimination and model performance.

Table 2. Random forest classifier performance averaged over 10-fold validation.

	TPR	FPR	PPV	NPV	Accuracy
Random Forest	0.78	0.5	0.8	0.87	0.87

The performance of the random forest classifier is presented in Table 2. We can observe that the TPR is high with a lower FPR. This means that the classifier is capable of accurately predicting the patients with high mortality risks. High PPV and NPV values further signify that the classifier is capable of identifying the patients who are at high risk of mortality correctly, as well as the patients who are not at risk of mortality respectively. The mean results for ROC curves across each fold are presented in Figure 1 to show the consistency in prediction. A mean area of 0.79 under the ROC curve in Figure 1, suggest that most of the high risk patients in the ICU are correctly identified.

Traditionally in hospitals, SAPS-1 score [5] is often associated with ICU mortality prediction value. According to the Physionet challenge [3], the minimum of TPR and

PPV was used as a metric to evaluate the performance of prediction model with 1 being the most accurate and 0 the least. The SAPS-1 score in the challenge [3] however measured as 0.296 compared to our model score of 0.78 evaluated on the same dataset. This indicates that random forest classifier provides a better risk prediction model. Random guessing however, with the same dataset provided a score of 0.139 in the Physionet challenge [3].

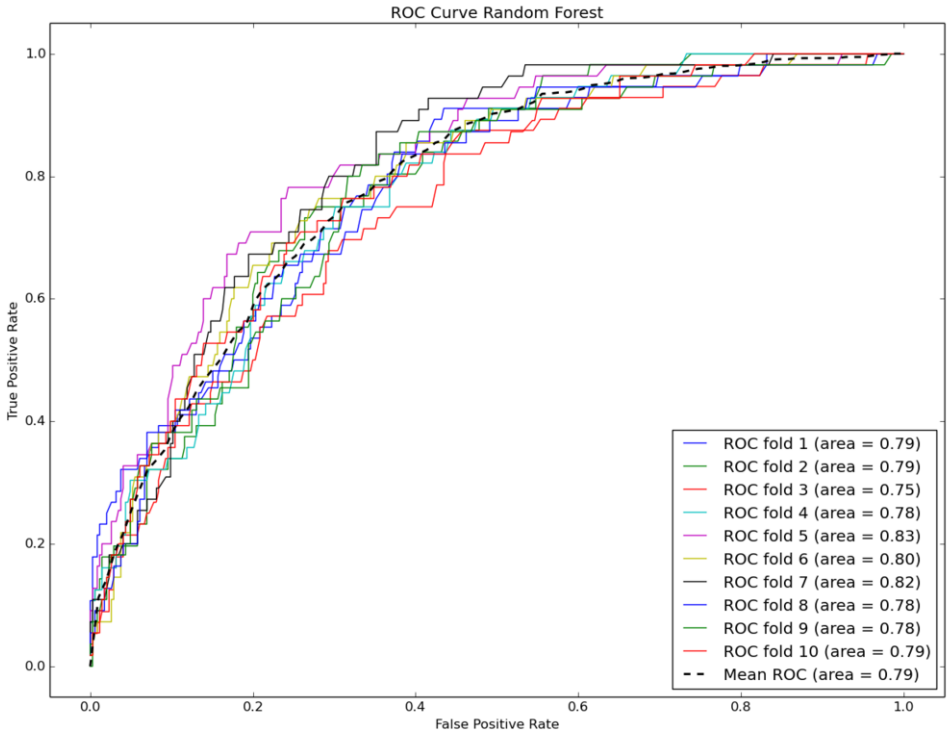

Figure 1. Random forest ICU mortality prediction ROC curves for each fold.

3. Discussion

Our random forest model for predicting mortality in ICU patients demonstrates a certain degree of variation in the 10-fold cross validation, with the area under the curve as high as 0.83 and as low as 0.75 across the different folds. This suggests that noisy feature vector measurements affect the classifier's performance. There is however some inherent advantages of using a random forest classifier over traditional classification methods in such a case. Random forest allows bagging i.e. random sub-sampling of both the feature space and feature values to set thresholds in order to create a weak classifier (decision trees). In presence of noisy feature values, some of the trees will provide a high training error, however the overall performance remains unaffected as the prediction probabilities are averaged over a large number of trees. This

characteristic feature of a random forest classifier being robust to noise is typically observed from the high average value of area under the curve (Figure 1).

In Physionet challenge minimum of TPR and PPV was used to judge the performance of the prediction model. A score of 0.78 achieved with our random forest algorithm was significantly higher than the performance of the SAPS-1 score of 0.296 that was used as the benchmark for comparison in the challenge [3] and our study. A wide variety of machine learning approaches were employed for mortality prediction as part of the Physionet challenge These models varied from logistic regression, to support vector machines (SVM), to Bayesian ensemble of decision trees [7]. Prediction accuracy score of some models participating in the challenge is unavailable and thus could not be compared. Logistic regression approach of Bera et al. [7] returned a score of 0.44, while the cluster analysis approach of Xu et al. [8] returned a score of 0.39, SVM prediction of Bosnjak et al. [9] returned a score of 0.71, and the Bayesian ensemble learning approach of Johnson et al. [10] returned a score of 0.30 compared to our random forest model score of 0.78. We hypothesise that the improved performance of our model is in line with the established superiority of random forest classifiers in dealing with missing data [11]. Given that the static and the time series variables contain missing data, random forest classifier is well suited for such a scenario.

4. Conclusion

An automatic ICU mortality risk prediction system has been proposed with a random forest classifier. The method outperforms the traditional SAPS-1 scoring method often used in hospitals. In future, this work may be extended to develop a risk prediction system from patient's real-time state to alert health personnel for timely care and intervention.

References

[1] I. Silva et al., Predicting In-Hospital Mortality of ICU Patients: The PhysioNet/Computing in Cardiology Challenge 2012. *Comput Cardiol (2010)*. 2012;39:245-248.
[2] Andy Liaw and Matthew Wiener, *Classification and Regression by Random Forest,* JML. R News, 2002, pp. 18-22.
[3] J. R. Le Gall et al., *A simplified acute physiology score for ICU patient.* Critical Care Medicine, vol. 12, pp. 975-977, 1984.
[4] Physionet *Challeng, http://physionet.org/challenge/2012/* , accessed on [14th March, 2015].
[5] Bera et al., *Mortality Risk Assessment of ICU Patients using Logistic Regression,* http://www.cinc.org/archives/2012/pdf/0493.pdf , accessed on [14th March, 2015].
[6] Xu et al., *CinC Challenge: Cluster Analysis of Multi-Granular Time-series Data for Mortality Rate Prediction,* http://www.cinc.org/archives/2012/pdf/0497.pdf , accessed on [14th March, 2015].
[7] Bosnjak et al., *Predicting Mortality of ICU Patients Using Statistics of Physiological Variables and Support Vector Machines,* http://www.cinc.org/archives/2012/pdf/0481.pdf , accessed on [14th March, 2015].
[8] Johnson et al., *Patient Specific Predictions in the Intensive Care Unit Using a Bayesian Ensemble,* http://www.cinc.org/archives/2012/pdf/0249.pdf, accessed on [14th March, 2015].
[9] L. Breiman, *Random forests*. Machine Learning, vol. 45, 2001.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-62

Human Activity Recognition from Smart-Phone Sensor Data using a Multi-Class Ensemble Learning in Home Monitoring

Soumya GHOSE [1], Jhimli MITRA [1], Mohan KARUNANITHI [1] and Jason DOWLING [1]
[1] *Australian e-Health Research Centre, CSIRO, Digital Productivity Flagship.*

Abstract. Home monitoring of chronically ill or elderly patient can reduce frequent hospitalisations and hence provide improved quality of care at a reduced cost to the community, therefore reducing the burden on the healthcare system. Activity recognition of such patients is of high importance in such a design. In this work, a system for automatic human physical activity recognition from smart-phone inertial sensors data is proposed. An ensemble of decision trees framework is adopted to train and predict the multi-class human activity system. A comparison of our proposed method with a multi-class traditional support vector machine shows significant improvement in activity recognition accuracies.

Keywords. Activity recognition, support vector machines, random forest

Introduction

The number of Australians aged 65 and over is expected to increase rapidly from 13 per cent of the population to 25 per cent of the population by 2042 [1]. Managing the ever increasing cost of delivering healthcare to the ageing population is a major challenge. Assisting the chronically ill and aged population accounted for over 70% of Australia's 103.6 billion dollar health expenditure during 2007-2008, that is only likely to increase [2]. This expenditure may be reduced by remote monitoring of aged or chronically ill patients that in turn may potentially reduce the frequency of hospitalisations. Helping patients self-manage their conditions at home through the provision of tele-health services and remote monitoring by health workers enables timely intervention. The success of such a system often requires prediction of the patient activities such as sleeping and walking.

In remote monitoring of patient, often specific sensors measuring heart rate, blood pressure, blood glucose and body temperature are used to collect patient-specific data. Recent advances in sensor technology have allowed the integration of these sensors in smart-phones, thus, allowing seamless tracking of activities with smart-phone sensors such as accelerometer and GPS. For example, activity monitoring like walking or lying

[1] Corresponding author: Soumya Ghose, The Australian e-Health Research Centre, CSIRO, Level 5 - UQ Health Science Building 901/16, Royal Brisbane and Women's Hospital, Herston Qld 4029 Australia; E-mail: Soumya.Ghose@csiro.au

is of critical importance for an elderly person or sick patient. Therefore, sensor data from the smart-phone GPS or accelerometer may be used in identifying the patient's state.

Activity recognition aims to identify the actions carried out by a person given a set of observations from inertial sensors such as accelerometer and gyroscope. The primary objective of this work is to use multi-class ensemble learning to predict a set of physical activities like standing, walking, laying, and walking upstairs and downstairs from the accelerometer and gyroscope sensor data. The data from the smart-phone can be uploaded to a remote server at a certain time interval and then the machine learning framework can predict the patient's activity state from that data. The sampling rate of the procedure is however application dependent. For example, a chronically ill patient may be monitored more frequently compared to an elderly person with health conditions only related to ageing.

All such remote monitoring however generates large amount of data and it is time consuming to manually predict a patient's activity from the sensor data. Multi-class classifiers provide an elegant solution to such a problem. In this work, an ensemble of decision trees (random forest) is trained with the sensor data related to a set of physical activities. Given a new set of sensor data, the random forest classifier predicts the patient's activity from the learned model.

The rest of the paper is structured in the following manner; the state of the art in activity recognition is presented in Section 2, methodological details of the multi-class ensemble of decision trees classifier is presented in Section 3 and the results are presented in Section 4.

1. Related Work

The use of smart-phone in remote monitoring of patient activities has several advantages. Smart-phones are portable, convenient to use and relatively in-expensive compared to full-body sensor apparel [3]. The use of numerous sensors may improve activity prediction accuracies and with technological advancements, smart-phone sensors are increasingly becoming more accurate. One major drawback of smart-phone based sensors, however, is sharing of resources like processing power and memory with other applications. Nonetheless, smart-phones have become an integral part of our life allowing easy collection of sensor data. These data may be further analysed with machine learning methods to classify an activity.

Several machine learning methods including Naïve-Bayes classifiers, support vector machines (SVM), threshold based methods and Markov models have been used for activity recognition [3]. Activity recognition with a multi-class SVM produced promising results [3]. Traditionally, SVM is a binary classifier. The classifier was extended to a multi-class classifier using a one-versus-the-rest classification strategy [4]. SVM provides a linear decision surface maximising the margin of separation between two classes. Non-linear kernel functions may be chosen for SVM where the data is not linearly separable; however, the choice of such a kernel is not straightforward. In many cases, the projection of data into a higher dimension does not capture the intrinsic properties of the features that can actually discriminate between the classes. A random forest [5] on the other hand provides a non-linear decision surface as an aggregation of piece-wise linear decision surfaces obtained from the decision trees. Therefore, in this work we have used the multi-class random forest

classifier that can be easily applied for the multi-class activity recognition problem and compared its performance with the one-versus-the-rest multi-class SVM classifier performance [4].

2. Method

A random decision forest is a supervised learning method and is an ensemble of decision trees. A decision tree is a set of two types of nodes, the split nodes and the leaf nodes. In order to train a model, the training feature space is randomly sampled with uniform sampling of the feature thresholds at each split node with the aim of maximising the information gain [5]. Therefore, each split node stores a decision function, while the empirical distribution of the posterior probability $p(y \mid x)$ of assigning label y to the training data x is stored at the leaf nodes.

To predict the label of a new data x, the feature is pushed down through the learned split functions and once it reaches the leaf node, the stored distribution $p(y \mid x)$ is used to predict the label. The overall prediction of the forest with T decision trees is finally obtained by averaging the individual tree prediction as follows,

$$p_t(y \mid x) = \frac{1}{T} \sum_{t=1}^{T} p_t(y \mid x) \tag{1}$$

Each of the decision trees in a random forest is a weak classifier and an aggregate of their individual predictions is used to obtain a final prediction. A single decision tree is known to suffer from over-fitting [6], while, a random forest offers better generalisation capabilities by randomising the features and feature threshold values at the split nodes. In this work, the number of trees was fixed to 200 and depth was fixed as 7 to reduce over-fitting.

A public dataset from [7] was used to evaluate the classifier performance. The experiments were carried out on a group of 30 volunteers within an age bracket of 19-48 years. The experiments were further video tagged to aid in data labelling. Each participant performed six activates (sitting, standing, walking, laying, walking upstairs and walking downstairs) wearing a Samsung Galaxy S2 smart-phone. The data from the accelerometer and gyroscope, measuring 3-axial linear accelerations and angular velocity respectively at a constant rate of 50Hz were captured for activity recognition. The sensor data were pre-processed by applying a Gaussian noise reduction filter and then re-sampled in fixed-width sliding windows of 2.56 sec with 50% overlap. From each window, a vector of time and frequency domains features of the accelerometer signal is extracted. Mean, standard deviation, signal magnitude area, entropy, signal-pair correlation, and Fourier Transform were used to extract the frequency components of the signal. The features were used as inputs along with the activity label to train a random forest classifier.

3. Results

The public dataset was randomly partitioned into 70% training and 30% testing samples. The common evaluation metrics like the true positive rate, false positive rate and precision were measured. The metrics were computed as follows:

$$\mathrm{TPR} = \mathrm{Sensitivity} = \mathrm{Recall} = \frac{\mathrm{TP}}{\mathrm{TP} + \mathrm{FN}},$$

$$\mathrm{FPR} = \frac{\mathrm{FP}}{\mathrm{FP} + \mathrm{TN}},$$

$$\mathrm{Precision} = \frac{\mathrm{TP}}{\mathrm{TP} + \mathrm{FP}}.$$

The Receiver Operating Characteristic (ROC) curves for each class prediction along with the average prediction by random forest are presented in Figure 1. In Figure 1, we can observe both true positive rate (TPR) and the false positive rate (FPR) of the multi-class classifier are very high.

As observed in Table 1, the classifiers scores a perfect or near perfect scores in terms of precision and recall in activity recognition of walking, standing, sitting and laying. The classifier scores comparatively low in terms of precision and recall for walking upstairs and walking downstairs. We believe this is more related to gyroscope values that were recorded. A more sensitive gyroscope sensor is probably needed to distinguish between walking upstairs and downstairs.

In this work we quantitatively compared the activity recognition accuracy results with a previously published work of Anguita et al. [4] validated on the same public dataset (Table 1). Anguita et al. used an extended SVM to adapt to a multi-class activity recognition framework. As observed in Table 1, our proposed random forest classifier performs better in all the activity classes in terms of precision and recall. A maximum value of 1 for precision and recall was achieved for the “Laying” class by both the compared approaches.

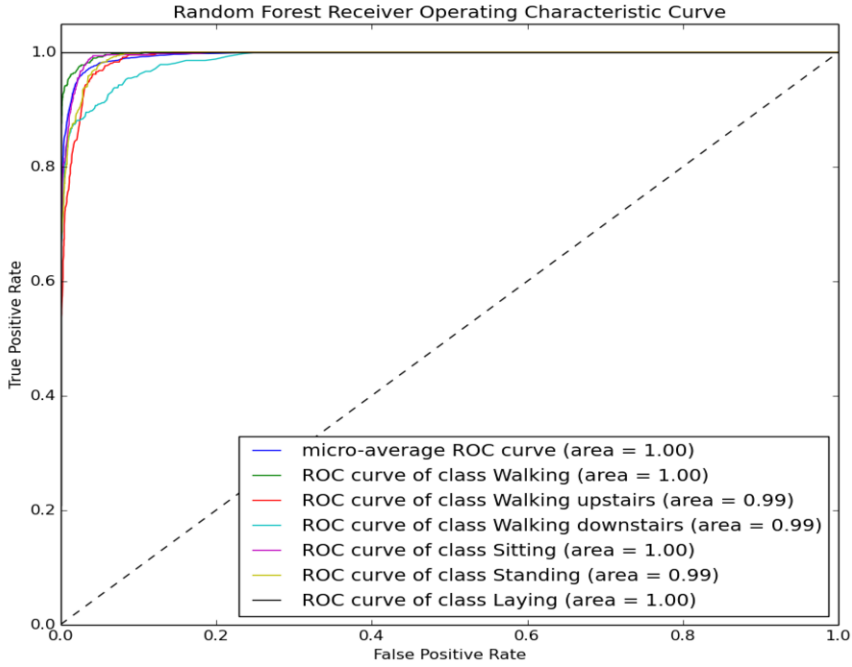

Figure 1. Random forest activity recognition ROC curves for each activity class and the average ROC.

Table 1. Quantitative comparison of SVM [4] and our proposed random forest framework.

Activity	Metrics	SVM [4]	Random Forest (proposed)
Walking	Recall	0.95	0.99
	Precision	0.87	0.99
Walking Upstairs	Recall	0.72	0.97
	Precision	0.81	0.94
Walking Downstairs	Recall	0.79	0.98
	Precision	0.74	0.95
Standing	Recall	0.92	1
	Precision	0.97	0.98
Sitting	Recall	0.96	0.99
	Precision	0.94	0.98
Laying	Recall	1	1
	Precision	1	1

4. Conclusion

An automatic activity recognition system has been proposed with a random forest classifier. The proposed method performs slightly better than support vector machine proposed by [4]. The method however, needs to be validated with a larger dataset. In future, this work may be extended to develop a risk prediction system from patient's activity state to alert health personnel. Accurate activity prediction system for the elderly with the proposed model may potentially reduce the risk associated with remote monitoring. Additional sensor data from heart rate monitoring and body temperature may be easily incorporated as features in the classification system to design a patient – specific and illness-specific remote risk assessment system.

References

[1] Australian Government, Australia's Demographic Challenges, http://demographics.treasury.gov.au/content/_download/australias_demographic_challenges/html/adc-04.asp, accessed on [14th March, 2015]

[2] CSIRO, Home Monitoring of Chronic Disease for Aged Care, http://www.csiro.au/en/Research/DPF/Areas/Digital-health/Improving-access/Home-monitoring, accessed on [14th March 2015].

[3] A. Mannini et al., Machine Learning Methods for Classifying Human Physical Activity from On-Body Accelerometers,Sensors, vol. 10, pp. 1154-1175, .

[4] D. Anguita et al., Human Activity Recognition on Smartphones using a Multiclass Hardware-Friendly Support Vector Machine, Proc. IWAAL, pp. 216-223, 2012.

[5] Andy Liaw and Matthew Wiener, Classification and Regression by Random Forest, JML. R News, pp. 18-22, 2002.

[6] L. Breiman, Random forests. Machine Learning, vol. 45, 2001.

[7] UCI machine learning repository, Human Activity Recognition Using Smartphone Dataset,archive.ics.uci.edu/ml/datasets/Human+Activity+Recognition+Using+Smartphones, accessed on [14th March 2015].

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-68

Health Informatics and E-health Curriculum for Clinical Health Profession Degrees

Kathleen GRAY [a], Dawn CHOO [a], Kerryn BUTLER-HENDERSON [b], Sue WHETTON [c] and Anthony MAEDER [d]
[a] *Health and Biomedical Informatics Centre, The University of Melbourne, Melbourne, Australia*
[b] *Centre for Rural Health, University of Tasmania, Launceston, Australia*
[c] *Tasmanian School of Business and Economics, University of Tasmania, Launceston, Australia*
[d] *School of Computing, Engineering & Math, University of Western Sydney, Sydney, Australia*

Abstract. The project reported in this paper models a new approach to making health informatics and e-health education widely available to students in a range of Australian clinical health profession degrees. The development of a Masters level subject uses design-based research to apply educational quality assurance practices which are consistent with university qualification frameworks, and with clinical health profession education standards; at the same time it gives recognition to health informatics as a specialised profession in its own right. The paper presents details of (a) design with reference to the Australian Qualifications Framework and CHIA competencies, (b) peer review within a three-university teaching team, (c) external review by experts from the professions, (d) cross-institutional interprofessional online learning, (e) methods for evaluating student learning experiences and outcomes, and (f) mechanisms for making the curriculum openly available to interested parties. The project has sought and found demand among clinical health professionals for formal health informatics and e-health education that is designed for them. It has helped the educators and organisations involved to understand the need for nuanced and complementary health informatics educational offerings in Australian universities. These insights may aid in further efforts to address substantive and systemic challenges that clinical informatics faces in Australia.

Keywords. Clinical informatics, clinical workforce, competencies, design-based research, e-health education, health informatics education, interprofessional education, online learning, quality assurance

Introduction

The rise of e-health around the world calls for new health informatics knowledge and skills in the clinical workforce. [1] In Australia as elsewhere 'health informatics' is the preferred term for the foundation discipline area and 'e-health' for the internet application area. [2] These terms are in common usage across a range of clinical professional practitioners who work directly with patients and clients. [3] Educational

planning and curriculum frameworks for this area of education in the clinical health professions have received attention nationally and internationally for over a decade. [4], [5]

The status of health informatics and e-health education in Australian clinical health profession degrees (i.e. specifically excluding non-clinical degrees such as business, engineering, information technology, life sciences) was the focus of baseline research from 2010-2013. [6] That research identified several localised and laudable curriculum initiatives, however it found that they were largely unknown beyond their home university so the majority of future clinicians in Australia did not benefit. Very few clinical degree programs had a systematic approach to teach, assess, evaluate or audit this aspect of professional education. Research and scholarship in this area were inactive compared to other areas of health professions education.

That study also identified systemic problems for the advancement of health informatics and e-health education: Learning, teaching and assessment resources that were up-to-date and appropriate for the Australian health system were scarce. Lecturers, tutors and placement supervisors lacked knowledge and experience to teach in this area. Graduate recruitment by healthcare organisations did not recognise this as a distinct area of expertise. Although some movement was evident (e.g. [7]), standards for accrediting degrees (e.g. [8]) and certifying practitioners (e.g. [9]) overall did not specify health informatics and e-health competencies.

The challenge of advancing health informatics and e-health education at scale in clinical health profession degrees in Australia cannot be satisfactorily addressed by individuals in separate institutions offering bespoke subjects at a local level. From the perspective of regulating the clinical professions, that approach is outside the governance processes for education in the clinical health professions. From the perspective of recognising the discipline and profession of health informatics, that approach does not map onto national or international recommendations for health informatics curriculum and competencies in any transparent or accountable way.

The aim of this paper is to report on a 2014-2015 clinical informatics and e-health subject (i.e. a unit of study) development project that models a new approach. This project's objective is to address the challenge of providing education that is widely available to students in a range of clinical profession degrees nationally. Additionally, this project introduces educational quality assurance practices which are consistent with university qualification frameworks, and with clinical health profession education standards, while at the same time it gives due recognition of health informatics as a specialised profession in its own right.

1. Methods

This project can be understood as educational research in terms of a design-based research methodology: It is characterised by being situated in a real educational context; focusing on the design and testing of a significant intervention; involving multiple iterations; contributing to the evolution of design principles; and having an impact on practice. [10]

The project has used mixed methods. The key methods used to address quality assurance are: (a) design with reference to university qualification levels and health informatics competency standards, (b) peer review within a multi-university teaching team, and (c) external review by experts from the professions. The key methods to

address the challenge of national availability are: (d) offering an online learning option that allows cross-institutional and interprofessional enrolment, (e) evaluating student learning experiences and outcomes, and (f) making the curriculum openly available to interested parties. This paper reports results of subject development quality assurance methods and foreshadows results regarding availability, in the next section.

2. Results

The subject was designed to be offered at postgraduate level, or Australia Qualifications Framework level 8. [8] At this level the Australian university system offers a range of entry-level Masters degrees in the clinical professions as well as specialist certificates, diplomas and degrees. The subject directly responded to the creation - in the final year of the national baseline study - of a new set of 52 competencies in six domains for the certification of professional health informaticians in Australasia (CHIA). [11] The curriculum was further informed by pre-existing published recommendations (e.g. those developed by the Australian Health Informatics Education Council [12], the International Medical Informatics Association [13], and others itemised in [14]) that had been mapped in the development of CHIA [15]. The subject adapted these competencies for offering over a 12-week semester as follows: Orientation week; Health and Biomedical Sciences (over 2 weeks); Information and Communications Technology; Information Sciences; Management Sciences; Core Principles and Methods (over 4 weeks); Human and the Social Context; Review week.

The team to develop and teach the subject was a joint initiative by three universities in three States; individual team members also had a history of collaboration in the educational activities of relevant professional organisations (e.g., Australasian College of Health Informatics, Australasian Telehealth Society, Health Informatics Society of Australia, Health Information Management Association of Australia). This team drew together three of the academics who had conducted the 2010 national study plus an additional academic with a strong track record as a health informatics educator. A research assistant was recruited who had characteristics similar to the target student group - a recent graduate of a postgraduate clinical degree, with an interest in information and communication technology in healthcare. The lead academic created an integrated learning design for the subject; each academic took responsibility for developing curriculum related to CHIA competencies that aligned with their greatest expertise; the research assistant managed the project so that all team members planned, reviewed and critiqued the first iteration of the curriculum and learning design as a whole.

A panel of experts to review the curriculum was invited from the CHIA Board and also from others who expressed an interest in this project or the original study, including health informatics and e-health experts as well as academic coordinators of clinical degrees and subjects. Their brief was to provide feedback via a confidential online survey, on our interpretation of the CHIA competencies, our designated learning activities and our selection of learning resources. Feedback was received from 20 reviewers: approximately one-fifth were from the CHIA Board, nearly two-thirds were academic coordinators of clinical education, and over four-fifths had previous experience developing health informatics or e-health curriculum. The feedback was positive overall, and indicated that that the curriculum was relevant to the clinical professions, was well-aligned with the CHIA competencies and would be interesting to

clinical degree students. The project team incorporated the expert feedback into the second iteration of the curriculum.

Designing the subject for online learning was a way to support access to the curriculum across geographical, institutional and professional boundaries. Online learning management used the Blackboard™ system of the lead university. Learning is designed to be somewhat self-directed, guided by a detailed study guide and a choice of weekly activities on a theme. Structured group learning is incorporated through asynchronous interactions with the project team and other students, based on student work shared in discussion forums each week. Assessment is varied and progressive and uses staff and peer feedback: pre- and post- semester tests and surveys; a short piece of writing each week based on scholarly and industry resources available openly on the internet; and a literature review on a topic negotiated by the student and shared online in the final week.

A trial version of the subject started in March 2015 with the main aim of evaluating student learning experiences and outcomes. Students from across Australian university clinical health profession degrees were recruited via emails to university degree coordinators and deans and directors of teaching in health sciences and through the media channels of relevant professional organisations. Since the subject is not yet approved for credit towards a university degree, participants were offered incentives: free enrolment and a certificate of completion showing the standard of work achieved. We received over 40 expressions of interest, and 20 students from 10 clinical professions were selected for the trial. Quantitative and qualitative analysis of learning experience and outcome will look at: student participation, student assessment results, pre- and post- trial tests of informatics knowledge, and pre-and post-trial surveys to measure possible demographic and other factors, such as participants' internet communication skills and readiness for interprofessional learning. The experiences of both students and teaching team members during this trial are intended to inform further iterations of the learning design for the online subject, and one or more models for its ongoing operation as a credit-bearing university subject.

Open access to the final version of the curriculum – based on our interpretation of CHIA competencies, our designated learning activities and our selection of learning resources – will be provided online via the project website (www.clinicalinformaticseducation.pbworks.com) at the conclusion of the student trial period in mid-2015. Open access to a more detailed report on the project including preliminary analysis of the trial will be available online later in 2015. Opening the curriculum adds further opportunities for all clinical degree coordinators to consider how to embed competencies into the core of their degree studies. Introductory elective subjects offered semester-by-semester are a partial solution only to the need for all clinical health professionals to be educated in health informatics as part of their professional practice.

3. Discussion

It was essential for our project to differentiate between technical / vocational, undergraduate and postgraduate levels of learning activities and learning outcomes in order to develop a subject that was appropriately located within the Australian Qualifications Framework. By using the framework of the CHIA competencies but setting aside the prescribed forms of knowledge (comprehension, application or

analysis) associated with specific CHIA competencies, we were able to design a curriculum that introduces postgraduate clinical professionals to the field. Questions around the equivalency between completing a postgraduate subject such as ours and passing the CHIA examination will require further consideration among the professional and educational bodies concerned.

We knew that the CHIA competencies were designed for intending health informatics practitioners regardless of their academic degree or career path, designed to certify as professionals people who were not necessarily clinically qualified, and designed as preparation for them to work not only in clinical settings but also in other health settings. Our adaptation of them was one possible way to structure health informatics and e-health education to equip clinicians with the necessary new forms of clinical capability. It is important to recognise that there is scope for further refinement in this curriculum model, or for other models altogether. It is also important to acknowledge that this model provides no more than a taster for clinicians seeking education in advanced clinical informatics specialisations. Nevertheless we decided that it was important to align this subject with the CHIA competencies because they represent a current broad Australian consensus in an environment of widespread and persistent conceptual chaos about the scope of "health information" work (e.g. [16]).

Working with the CHIA competencies in this project showed the need for clarification of some fundamental assumptions in these competencies, for example their use of undefined concepts such as good practice or best practice. It pointed up some of the areas where health informatics competencies may need to be updated to give more attention to the influence of e-health, for instance developments in more participatory, social technologies and more natural, ambient user interfaces to information. It also highlighted the demand for further work on still underdeveloped CHIA specialisations - in clinical informatics, clinical research informatics, nursing informatics, aged care informatics, and others. The project was able to reflect such observations back to the CHIA Board, thus providing a 360-degree quality process; the more projects such as ours that seek to apply these competencies, the more refined they can become.

4. Conclusion

Educational needs in this area of clinical health professions curriculum are dynamic. Further development of this subject and others in the field will need to respond to evolving national and international approaches to health informatics quality assurance of practitioners and education organisations (e.g. [17]). It will need to address changes to the scope of clinicians' professional practice with information and communication technologies that may unfold as health systems themselves evolve (e.g. [18]).

The project has made a contribution to principles in health informatics education design as well as having practical outcomes. It has not just laid the groundwork for a subject for university credit aimed at and accessible by clinical profession students in universities nationally. It has also modeled a process with which few Australian health informatics educators so far have worked, of internally and externally reviewing the design and operations of subjects and degree courses.

The project has sought and found demand among clinical health professionals for formal university-level education in health informatics and e-health, designed for clinicians. It has helped the educators and organisations involved to understand the need for nuanced and complementary health informatics educational offerings in

Australian universities. These insights may aid in further efforts to address the substantive and systemic challenges that clinical informatics faces in Australia.

Acknowledgements

Support for this project has been provided by the Australian Government Office for Learning and Teaching. The views in this project do not necessarily reflect the views of the Australian Government Office for Learning and Teaching.

We also acknowledge with gratitude the interest and input from individuals associated with CHIA and its auspicing organisations ACHI, HISA and HIMAA, as well as from clinical degree students and staff.

References

[1] K. Gray, E.H. Shortliffe, K. Ho, P. Taylor, M. Mars, M., Maeder, et al., Health informatics education for the clinical workforce, *Proceedings of MedInfo* (2013), 1233.
[2] E. Ammenwerth, G. Schreier, & D. Hayn, Health informatics meets eHealth. *Methods of Information in Medicine* **49** (2010), 269.
[3] Australian Bureau of Statistics, *Australian and New Zealand Standard Classification of Occupations. Sub-major Group 25. Health Professionals*, 2013.
[4] S. Hilberts, & K. Gray, Education as ehealth infrastructure: Considerations in advancing a national agenda for ehealth. *Advances in Health Sciences Education* **19** (2014), 115-127.
[5] S.E. Smith, L.E. Drake, J.G.B. Harris, K. Watson, K., & P.G. Pohlner, Clinical informatics: A workforce priority for 21st century healthcare. *Australian Health Review* **35** (2011), 130-135.
[6] K. Gray, A. Dattakumar, A. Maeder, K. Butler-Henderson, & H. Chenery, *Advancing Ehealth Education for the Clinical Health Professions Final Report*, Australia. Department of Education and Training, 2014.
[7] J. Foster, & J. Bryce, Australian nursing informatics competency project, *Proceedings of the 10th International Congress on Nursing Informatics: Connecting Health and Humans* (2009), 556-560.
[8] Australian Qualifications Framework, 2013. http://www.aqf.edu.au
[9] Australian Health Professions Regulatory Agency, 2013. http://www.ahpra.gov.au/Education/Accreditation-standards.aspx
[10] T. Anderson, & J. Shattuck, Design-based research: A decade of progress in education research?, *Educational Researcher* **41** (2012), 16-25.
[11] Certified Health Informatician Australasia Health Informatics Competencies Framework, 1.0, 2013. http://www.healthinformaticscertification.com
[12] Australian Health Informatics Education Council, *Health Informatics – Scope, Careers and Competencies,* 2011. http://www.ahiec.org.au/Documents.htm
[13] J. Mantas, E. Ammenwerth, G. Demiris, A. Hasman, R. Haux, W. Hersh, et al., Recommendations of the International Medical Informatics Association (IMIA) on education in biomedical and health informatics–1st revision. *Methods of Information in Medicine* **49** (2010), 105-120.
[14] W. Hersh, The health information technology workforce: Estimations of demands and a framework for requirements, *Applied Clinical Informatics* **1** (2010), 197-212.
[15] F. Martin Sanchez, IMIA Board Meeting, HaBIC Internal Report, University of Melbourne, 2012.
[16] Health Workforce Australia. *Health Information Workforce Report,* 2013. https://www.hwa.gov.au/our-work/health-workforce-planning/health-informaticians-specialist-workforce-study
[17] A. Hasman, & J. Mantas, IMIA accreditation of health informatics programs. *Healthcare Informatics Research* **19** (2013), 154-161.
[18] S. Leggat, *Changing health professionals' scope of practice: How do we continue to make progress?* Deeble Institute for Health Policy Research. Australian Healthcare and Hospitals Association, 2014. http://www.thedeebleinstitute.com/system/files/docs/publications/deeble_issues_brief_nlcg-4_changing_health_professionals_scope_of_practice.pdf

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-74

Automatic Detection of Skin and Subcutaneous Tissue Infections from Primary Care Electronic Medical Records

Yulong GU [a,1], John KENNELLY [a,b], Jim WARREN [a], Pritesh NATHANI [a] and Tai BOYCE [b]
[a] *University of Auckland, New Zealand*
[b] *The Fono Health & Social Services, Auckland, New Zealand*

Abstract. Introduction: Skin and subcutaneous tissue infections (SSTI) are common conditions that cause avoidable hospitalisation in New Zealand. As part of a program to improve the management of SSTI in primary care, electronic medical records (EMR) of four Auckland general practices were analysed to identify SSTI occurrences in the last three years. **Methods:** An ontology for SSTI risks, manifestation and treatment was created based on literature and guidelines. An SSTI identification algorithm was developed examining EMR data for skin swab tests, diagnoses (READ codes) and textual clinical notes. **Results:** High occurrence and recurrence rates in those aged 20 or younger were found. Due to low usage of READ coding and laboratory tests, 65% of SSTI occurrences were identified by notes. However, 91% of all identified SSTI occurrences were appropriately treated with oral/topical antibiotics according to prescription records in the EMR. The F_1 score of the analysis algorithm is 0.76 using manual review as gold standard. **Discussion and Conclusion:** The SSTI identification algorithm shows a reasonable accuracy suggesting the feasibility of automatic detecting SSTI occurrences using clinical data that are routinely collected in healthcare delivery.

Keywords. Skin and subcutaneous tissue infections (SSTI), staphylococcus aureus, streptococcus pyogenes, methicillin-resistant staphylococcus aureus (MRSA), electronic medical records (EMR), natural language processing

Introduction

Skin and subcutaneous tissue infections (SSTI) are infectious diseases often caused by staphylococcus aureus and/or streptococcus pyogenes bacteria. The SSTI rates have been rising in New Zealand (NZ), with clear social and ethnic inequalities reported in the disease risk factors [1-3]. The occurrence of serious SSTI in NZ children almost doubled from 298 per 100,000 in 1990 to 547 per 100,000 in 2007, with the direct cost estimated at NZ$15 million [4]. SSTI Hospital admissions significantly underestimate the burden of disease on the communities most affected by this communicable disease. It is estimated from a sample of primary care data in Tairawhiti region of NZ, that the annual rate of primary care cases for SSTI is 106.7 cases per 1000 children (0-14 years) [5]. Comparing with hospital admission data in the same region, there were 14 primary care skin infections for every hospital admission. By comparison the incidence rate of

[1] Corresponding Author: Yulong Gu, University of Auckland, New Zealand; Email: h.gu@auckland.ac.nz.

impetigo in primary care in the Netherlands is approximately 20 cases per 1000 accompanied by a significant departure from the national guideline for treatment [6].

Antibiotics have been found effective in treating SSTI [7, 8] and are recommended, including oral, topical, and intravenous therapy (IV) antibiotics, by local and international clinical guidelines. The importance of this serious communicable disease epidemic cannot be underestimated Delaying treatment or non-adherence to treatment for SSTI can lead to complications and sometimes hospitalisations. There is an urgent need to develop a public health approach to controlling the SSTI epidemic [4].

As part of a program aiming to improve the management of SSTI in primary care through the early identification of sentinel households with recurrent skin infections, this study explored the feasibility and performance of automatic detection of SSTI occurrences and recurrences by analysing ambient primary care electronic medical records (EMR). It is with rapid and accurate sentinel SSTI case identification utilising the EMR, that a public health response can be initiated and monitored for a reduction in incidence rates. It is possible that sentinel events could be characterised by recurrent infections in individuals or in households and appropriate and targeted public health measures could be instigated more successfully than the current treatment of individuals presenting at primary care. Four general practices in Auckland that serve large numbers of Pacific and Māori patients participated in the study. This paper reports on the development and performance of systematic SSTI identification algorithm, and findings regarding SSTI occurrence and recurrence rates in the sample.

1. Methods

1.1. EMR Data and Included Sample

The EMR data (demographic information, laboratory testing results, diagnoses, notes, and prescriptions between Oct/2011 and Oct/2014) of four participating general practices were extracted and analysed. The child and adolescent populations (age≤20) who are enrolled and funded at these practices were included in the study's main analysis to identify the rates of SSTI occurrences and recurrences. The ≤20 year-olds who were not funded at participating practices (e.g., enrolled elsewhere) but whose visiting records were maintained in these practices as 'casual' patients (in contrast to the enrolled and funded 'usual' patients) were included in the evaluation of the algorithm performance using their EMR data during the same 3-year period.

1.2. Development of SSTI Identification Algorithm

A skin swab laboratory test can confirm the presence of staphylococcus aureus, and/or methicillin-resistant staphylococcus aureus (MRSA), and/or streptococcus pyogenes colonies on the tested skin. Hence, these test results in the EMR were used to detect SSTI. The algorithm also searched for a set of disease diagnoses, including cellulitis, impetigo, subcutaneous abscess, boil, folliculitis, infected eczema, infected scabies, infected insect bites, infected abrasion and other bacterial skin infections (such as pyoderma and paronychia). These diagnoses were selected as the main categories of SSTI manifestation based on SSTI case definitions in literature [5] and clinical experience in the NZ primary care setting. A total of 311 diagnosis codes (READ Version 2 [9], as implemented in the practice EMR systems) that indicate SSTI were

selected. The READ terms and equivalent SNOMED [10] terms and synonyms were used in clinical notes processing for SSTI identification. Figure 1 depicts a high-level ontology for SSTI risks, manifestation, and treatment based on literature, clinical guidelines [5, 11], and available ontologies such as Infectious Disease Ontology [12].

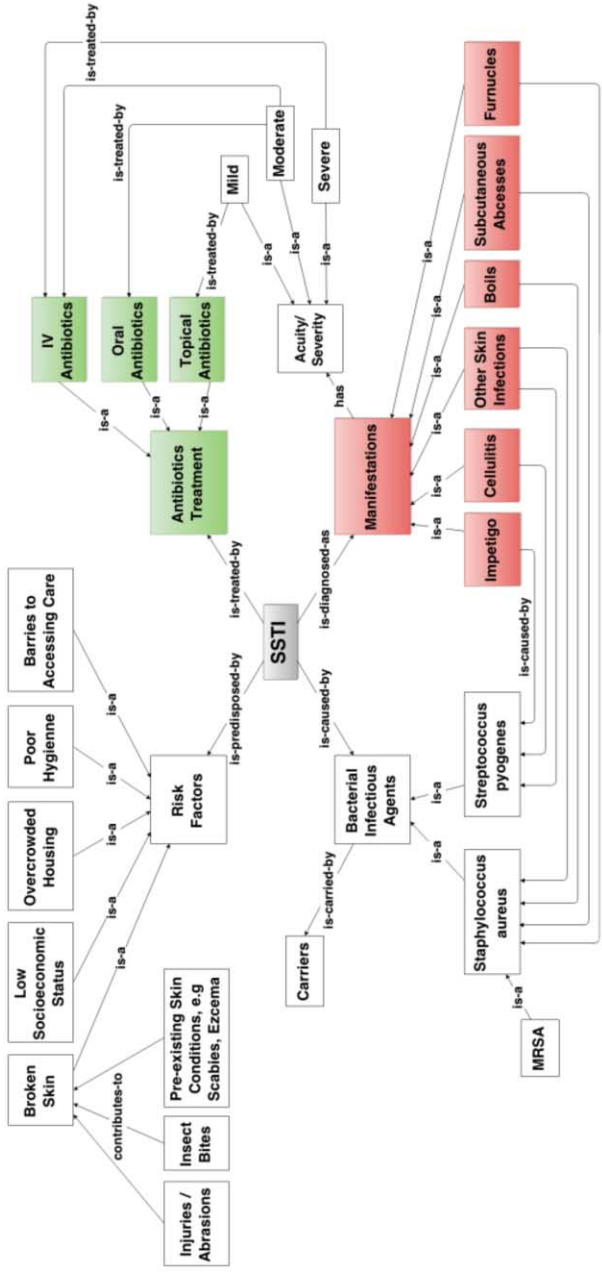

Figure 1. A high-level SSTI ontology.

As summarised in Figure 2, an SSTI occurrence can be detected from any of three data sources (laboratory test, READ-coded diagnosis, or notes indication). A second SSTI occurrence, if occurring >2 weeks after previous occurrence, is defined as a recurrence. SAS, version 9.2 was used in study analysis. Textual notes processing detected presence of selected READ / SNOMED terms and spelling variations of these terms, then discounted those associated with negation (e.g., 'no cellulitis'), personal history, or family history / symptom. Each sentence in the notes corpus was examined by the processing algorithm, implemented in C#. A special case was chickenpox, which sometimes was confused with SSTI. Given low prevalence of chickenpox complications that involve bacterial infections, it was decided to exclude those occurrences where chickenpox and SSTI were indicated, unless there was laboratory confirmation of bacterial agents. Antibiotics prescriptions issued in the identified SSTI occurrences were also examined to understand the treatment pattern in primary care.

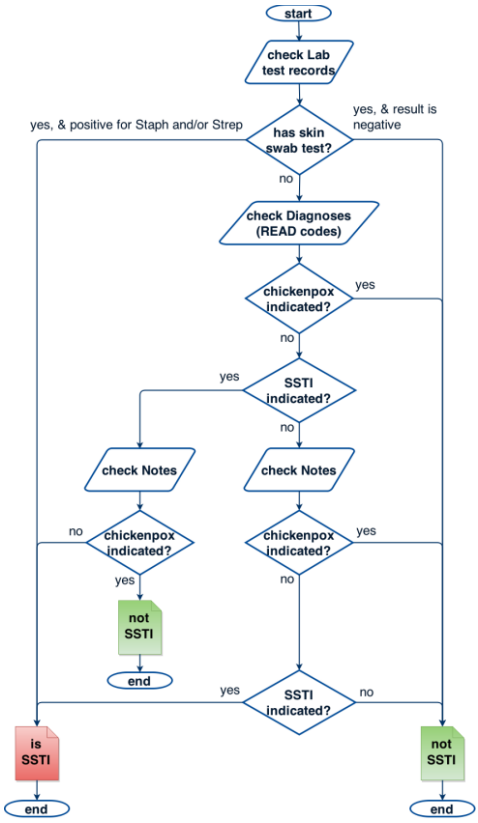

Figure 2. SSTI identification process flowchart.

1.3. Evaluation of the SSTI Identification Algorithm

A random sample of unfunded ≤20 year-olds were used in the evaluation. The SSTI cases identified by the algorithm (as 'test outcome positive') were compared with those

identified by manual review ('condition positive'). PN and TB independently classified the EMR records into SSTI and non-SSTI related cases; where different findings were found, JK (senior general practitioner) made the final decision. The algorithm accuracy is assessed in terms of positive predictive value (PPV or precision), sensitivity (or recall), specificity, negative predictive value (NPV) and F_1 score ($2 \cdot \frac{\text{precision} \cdot \text{recall}}{\text{precision} + \text{recall}}$).

2. Results

A total of 3,886 ≤20 year-olds living in 1,833 households were included in the main analysis. 1,382 individuals (36%) from 864 house-holds (47%) had an average of two SSTI occurrences in the last three years (total SSTI occurrence number = 2,714). Taking the whole funded population in this age group at the participating practices (N=3,886) as denominator, SSTI occurrence rate was 230 per 1000 person-year. According to the EMR prescription records, 91% of identified SSTI occurrences were treated with oral antibiotics (e.g., penicillin) or topical antibiotics (e.g., fusidic acid).

Low level of use of the READ codes and swab tests in identified SSTI occurrences was observed. Among all identified SSTI occurrences, only 22% were coded with a READ diagnosis and 16% were confirmed by skin swab tests. Only 7% of SSTI cases didn't have note entries that can be associated with SSTI, hence, were identified by READ diagnosis and/or laboratory results. On the other hand, 65% SSTI occurrences had neither diagnosis records nor laboratory records, i.e., identified by notes only.

The EMR data regarding 1,245 casual patients (unfunded, aged ≤20) were maintained in the participating practices. A random sample of 200 of these patients was included in the evaluation of the algorithm performance. Not unexpectedly, only some of these casual patients visited the general practices during the study period. EMR entries regarding 89 (45% of the 200 randomised) individuals were recorded on 307 days, collectively. Using manual review findings in assessing the algorithm accuracy, the truth table was calculated, as shown in Table 1. The PPV of the analysis algorithm was 64%, sensitivity = 94%, specificity = 97%, NPV=99.6%, and F_1 score = 0.76.

Table 1. Truth table on the performance of the SSTI identification algorithm.

	Condition positive	**Condition negative**
Test outcome positive	16	9
Test outcome negative	1	281

3. Discussion

EMR analysis identified high SSTI occurrence and recurrence rates in population aged ≤20. These rates are much higher than that reported in Tairawhiti region of NZ [5] and Netherlands [6]. This indicates an opportunity to improve SSTI management in the community, perhaps by firstly identifying high-risk population. For instance, SSTI identification (e.g. applying algorithm) may be used in clinical quality improvement

initiatives for 1) recruiting patients for follow up, 2) assessing size of the problem, for funding and planning purposes, and 3) evaluating intervention effect. To effectively manage SSTI risk in the community, a strategy needs to be developed to implement systematic risk identification and targeted interventions, e.g., screening, education, early treatment, and social/economic support to address a range of risk factors associated with infections, including socioeconomic factors such as overcrowding.

Low-level use of READ codes challenges the approach of using diagnosis alone in SSTI identification studies despite that high PPV was found using ICD-9 codes only [13]. Via note text mining, without checking diagnosis or laboratory results, 93% of SSTI occurrences had been identified in our study. This suggests that diagnosis codes and laboratory results might not add as much value as expected in such analysis.

The study has a few limitations; as a scoping study to test a methodology for automatic detection of SSTI, it included a small number of general practices in one metropolitan region, which may not represent medical centers or the population in other settings. Another limitation relates to the discrepancy in SSTI case definitions; the conditions included in this study were manually curated by JK based on lists suggested in literature and the existing data in the sample. These may not be easily adaptable to other settings. UMLS was not used in the note text mining due to two reasons: 1) the set of concepts regarding SSTI diagnoses and symptoms that were manually selected in this study is a relatively small set; and 2) Some of the terms used in notes that indicated SSTI are not included in SNOMED terms, e.g., “school sores”. The limitation of text mining also relates to the complexity of notes processing. This is well acknowledged given the variations of style of writing and sometimes ambiguous texts of which the interpretation depends on the clinician’s habits and preferences. Continuous effort will be made to refine the analysis algorithm, particularly regarding the notes text mining methods. And further evaluation using more cases is planned.

4. Conclusion

The analysis of general practice EMR data proved that it is feasible to automatically detect SSTI from the data collected as part of routine primary care delivery. The identified high occurrence and recurrence rates for SSTI in population aged 20 or younger indicate an opportunity to improve SSTI risk management in the community.

Acknowledgement

This study was funded by a University of Auckland School of Population Health Performance-Based Research Fund (PBRF) Distribution Seeding Grant.

References

[1] Baker MG, Barnard LT, Kvalsvig A, Verrall A, Zhang J, Keall M, et al. Increasing incidence of serious infectious diseases and inequalities in New Zealand: a national epidemiological study. Lancet. 2012;379(9821):1112-9.

[2] Finger F, Rossaak M, Umstaetter R, Reulbach U, Pitto R. Skin infections of the limbs of Polynesian children. The New Zealand medical journal. 2004;117(1192):U847.

[3] Williamson DA, Ritchie SR, Lennon D, Roberts SA, Stewart J, Thomas MG, et al. Increasing incidence and sociodemographic variation in community-onset Staphylococcus aureus skin and soft tissue infections in New Zealand children. The Pediatric infectious disease journal. 2013;32(8):923-5.
[4] O'Sullivan CE, Baker MG, Zhang J. Increasing hospitalizations for serious skin infections in New Zealand children, 1990-2007. Epidemiology and infection. 2011;139(11):1794-804.
[5] O'Sullivan C, Baker MG. Skin infections in children in a New Zealand primary care setting: exploring beneath the tip of the iceberg. The New Zealand medical journal. 2012;125(1351):70-9.
[6] Koning S, Mohammedamin RS, van der Wouden JC, van Suijlekom-Smit LW, Schellevis FG, Thomas S. Impetigo: incidence and treatment in Dutch general practice in 1987 and 2001--results from two national surveys. Br J Dermatol. 2006;154(2):239-43.
[7] Kilburn SA, Featherstone P, Higgins B, Brindle R. Interventions for cellulitis and erysipelas. The Cochrane database of systematic reviews. 2010(6):CD004299.
[8] Koning S, van der Sande R, Verhagen AP, van Suijlekom-Smit LW, Morris AD, Butler CC, et al. Interventions for impetigo. The Cochrane database of systematic reviews. 2012;1:CD003261.
[9] Health and Scocial Care Information Centre. Read Codes Leeds, England: Health and Social Care Information Centre; 2015 [cited 2015 Jan 30]. Available from: http://systems.hscic.gov.uk/data/uktc/readcodes
[10] International Health Terminology Standards Development Organisation. SNOMED CT: The Global Language of Healthcare Copenhagen, Denmark: International Health Terminology Standards Development Organisation; 2015 [cited 2015 Jan 30]. Available from: http://www.ihtsdo.org/snomed-ct
[11] HealthPoint Ltd. Northern Region Clinical Pathway for the Assessment and Management of Skin Infections in Children >3 Months - 14 Years Auckland: HealthPoint Ltd; 2013 [updated July 2013; cited 2015 Jan 30]. Available from: http://www.healthpointpathways.co.nz/northern/paediatric-a-z/skin-infections-paediatric-1/skin-infections-paediatric-diagnostic-algorithm/
[12] Infectious Disease Ontology Consortium. Infectious Disease Ontology: Infectious Disease Ontology Consortium; 2015 [cited 2015 Mar 15]. Available from: https://code.google.com/p/infectious-disease-ontology/
[13] Levine PJ, Elman MR, Kullar R, Townes JM, Bearden DT, Vilches-Tran R, et al. Use of electronic health record data to identify skin and soft tissue infections in primary care settings: a validation study. BMC infectious diseases. 2013;13:171.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-81

Incidence Rate of Prediabetes: An Analysis of New Zealand Primary Care Data

Yulong GU [1], Jim WARREN, John KENNELLY,
Natalie WALKER and Matire HARWOOD
University of Auckland, New Zealand

Abstract. Introduction: Diabetes is a common disease affecting 9% of the adult population worldwide. People with impaired glucose tolerance ('prediabetes') are at high risk of progressing to type 2 diabetes. **Methods:** To understand prediabetes incidence rate, we analysed the electronic medical records (EMR) from 14 New Zealand general practices regarding patients aged ≥20 years and enrolled with the practices between 2009 and 2012. Prediabetes incidence rate was calculated by the number of patients with an initial HbA1c of 41-49 mmol/mol in 2011 among those who had not been diagnosed or treated for diabetes. **Results:** 28,192 adults were included in the analysis, 11% of this cohort had diabetes before 2011. 1,276 new cases of prediabetes were identified in 2011, giving a 5.0% incidence rate. The relative risk (RR) for prediabetes was increased for the Māori and Pacific groups versus non-Māori/non-Pacific people, with RR of 1.97 in the younger age groups (<50 years) and RR of 1.42 in the 50+ group. The RR for having uncontrolled HbA1c (highest HbA1c in 2011 ≥65 mmol/mol) among the whole adult population was also increased for the Māori and Pacific groups versus non-Māori/non-Pacific people (RR = 3.35 among those <50 years, RR = 4.35 in the 50+ group). **Discussion and Conclusion:** EMR analysis identified an alarming incidence rate of prediabetes, especially among Māori and Pacific groups, highlighting the need to better prevent and manage the condition.

Keywords. Diabetes mellitus, prediabetes, HbA1c, incidence rate, prevalence

Introduction

Diabetes mellitus is a common non-communicable and chronic condition. According to the World Health Organisation (WHO), diabetes affects 9% of the world population aged 18+ years [1]. Diabetes has been recognised as a leading cause of premature death and disability; it also increases the risk of cardiovascular disease (CVD), kidney failure, blindness and lower-limb amputation. A WHO 2014 report stated that diabetes was directly responsible for 1.5 million deaths in 2012 and 89 million disability-adjusted life-years [2]. People with impaired glucose tolerance ('prediabetes' or 'intermediate hyperglycaemia') are at high risk for type 2 diabetes and CVD. In the long-term, up to 70% of people with prediabetes will eventually develop diabetes, according to an American Diabetes Association expert panel in 2012 [3]. However, lifestyle modification interventions have shown effectiveness in preventing or delaying the development of type 2 diabetes, by targeting obesity and physical inactivity [3]. An

[1] Corresponding Author: Yulong Gu, University of Auckland, New Zealand; Email: h.gu@auckland.ac.nz.

estimated 316 million people live with prediabetes internationally, with this number predicted to reach 471 million by 2035 [4].

In New Zealand (NZ), prediabetes is defined as an HbA1c level of 41-49 mmol/mol, and the NZ guidelines recommend practitioners provide advice to people with prediabetes about diet and lifestyle changes [5-7]. According to the 2012/13 NZ Health Survey, the overall diabetes prevalence in the population was 5.8%, with higher rates in Pacific (12.5%) and Māori (7.3%) people [8]. Recent population-based studies overseas have reported increasing rates of prediabetes, e.g., 55.4 per 1000 person-year in South Korea [9] and 32.3 per 1000 person-year in Iran [10]. However, to the best of our knowledge, there is little known about prediabetes incidence rate in NZ. Hence, this study set out to investigate the incidence rate of prediabetes in NZ primary care.

1. Methods

To understand prediabetes incidence rate and HbA1c control status in the general adult population, we analysed the electronic medical records (EMR) from 14 New Zealand general practices. The de-identified EMR data included in the analysis were collected in 2012 from twelve Auckland general practices and two Northland practices that use the MedTech32 EMR system. These data, including ethnicity, age, gender, enrolment information, diagnoses, prescriptions and physiological measurement results for the previous five years (including HbA1c), were collected for the baseline analysis in the Caring Does Matter (CDM) program, which was a Ministry of Health initiative to improve CVD risk management particularly in Pacific people through targeting CVD medication adherence gaps [11]. The patients who were aged ≥20 years in 2011 and had enrolled with the practices between 2009 and 2012 were included in the current analysis. Prediabetes was identified by meeting two criteria:

1. The patient had an initial HbA1c of 41-49 mmol/mol in 2011. In other words, there were either no prior HbA1c records in the EMR data (HbA1c records examined since 2008) or only HbA1c readings of 40 or less.
2. The patient had not been diagnosed with diabetes (if coded in READ Version 2 [12], or according to medication prescriptions, including oral antidiabetic medications and insulin, since 2008) by the first HbA1c of 41-49 time point.

There were two reasons for examining diabetes treatment in prediabetes identification. Firstly, the presence of antidiabetic medication prescriptions was used as a pseudo diagnosis of the disease. Secondly, having no antidiabetic medication prescriptions confirms that the HbA1c was not controlled by treatment. The Prediabetes incidence rate was then calculated using the number of patients with an initial HbA1c of 41-49 mmol/mol in 2011 as compared to those who had not been diagnosed or treated for diabetes before 2011. The age differences among the patients who were identified with prediabetes in 2011 among ethnic groups (Māori, Pacific, and non-Māori/non-Pacific) were examined using the Kruskal Wallis test. The relative risk (RR) for prediabetes was calculated comparing Māori/Pacific groups with non-Māori/non-Pacific people; and the RR for those <50 years of age and RR for the 50+ age group were reported separately. The HbA1c distribution was further examined among the prediabetes patients as well as among the whole adult population. RR for uncontrolled HbA1c (highest HbA1c in 2011 ≥65 mmol/mol [6]) was also calculated comparing Māori/Pacific group with non-Māori/non-Pacific people. SAS version 9.3

(SAS Institute Inc., Cary, North Carolina) was used in the analysis. (The EMR queries and the code lists used in the analysis are available from authors on request.)

2. Results

A total of 28,192 adults were included in the analysis, including 14,963 women (53%). The median age of this cohort is 48, with interquartile range (IQR) of 37-61. 13% of the cohort (3,543) consisted of Māori people (median age of 44, IQR: 32-54), 14% (4,052) were Pacific people (median age of 43, IQR: 32-55), and 73% (20,597) were non-Māori/non-Pacific people (median age of 50, IQR: 39-63).

2.1. Prediabetes Identification

A total of 2671 patients (9%) had pre-existing diabetes diagnosis or treatment by the end of 2010. During the year of 2011, 1,276 new cases of prediabetes, with an initial HbA1c of 41-49 mmol/mol, were identified, including 662 women (52%). The incidence rate of prediabetes in 2011 was 5.0%, see also Table 1. Among these patients who had prediabetes identified in 2011, Pacific (N=234, 50 years IQR: 42-60) and Māori (N=140, 51 years IQR: 44-61) patients were younger than non-Māori/non-Pacific patients (N=902, 62 years IQR: 52-71; $X^2 = 138$, $p<0.0001$). The relative risk (RR) for prediabetes was increased for the Māori and Pacific groups versus non-Māori/ non-Pacific people, with RR of 1.97 in the younger age groups (<50 years) and RR of 1.42 in the 50+ group.

Table 1. Prediabetes incidence by ethnicity and age group in 2011.

	Total number of patients	Patients who had diabetes before 2011 # (%)	Patients who had prediabetes identified in 2011 # (%)
Māori	3543	371 (10%)	140 (4%)
Pacific	4052	685 (17%)	234 (6%)
Non-Māori/non-Pacific	20597	1615 (8%)	902 (4%)
Total:	**28192**	**2671 (9%)**	**1276 (5%)**

In the same year of 2011, 199 new cases of diabetes were identified using READ coded diagnosis or medication prescription data, giving an incidence rate of 0.8%. These new diabetes patients included 24 (1.9%) of those identified with prediabetes in the year. In terms of HbA1c control in 2011 among all the prediabetes patients, none reached the uncontrolled HbA1c threshold (65 mmol/mol) within 2011; however, 8 patients had a high HbA1c of ≥50 mmol/mol.

2.2. HbA1c Control in the Cohort

Across the whole cohort, the RR for having uncontrolled HbA1c (highest HbA1c in 2011 ≥65 mmol/mol) was increased for the Māori and Pacific groups versus non-

Māori/ non-Pacific people (RR = 3.35 among those <50 years, RR = 4.35 in the 50+ group). Table 2 tracks the highest HbA1c readings each year from 2008 to 2011; and demonstrates a trend of reduction in the percentage of patients with uncontrolled HbA1c among all the patients who had at least one HbA1c test in the year.

Table 2. The distribution of HbA1c (mmol/mol) levels.

Year	Patient # with HbA1c	≤40	41-49	50-54	55-64	65-79	80-99	≥100	Total uncontrolled
2008	4404	33%	30%	9%	11%	9%	5%	3%	17%
2009	4310	35%	30%	10%	11%	9%	4%	3%	15%
2010	3798	29%	35%	10%	11%	8%	5%	2%	15%
2011	6194	31%	39%	9%	9%	7%	3%	3%	13%

3. Discussion

Diabetes is a common chronic condition that imposes a significant burden on health systems worldwide. The WHO 2014 report has recognised the increasing prevalence of diabetes globally, and particularly accelerated in low- and middle-income countries [2]. The diabetes prevalence in NZ has been estimated at 4.4% in 2009 using EMR data of multiple data sources [13, 14] and at 5.8% in the year 2012/13 using national health survey data [8]. Our analysis using primary care EMR data identified an even higher prevalence of 9% by the end of 2010, with an incidence rate of 0.8% in 2011. The increasing trend of the disease is consistent to that reported internationally [9, 10].

The EMR data in our study also revealed an incidence rate for prediabetes of 5.0% in 2011. Furthermore, risk for prediabetes was elevated for the Māori and Pacific groups versus non-Māori/ non-Pacific people, especially in the younger age groups. Given the already high prevalence of diabetes in Māori and Pacific groups, this highlights the need to better prevent and manage disease progression. Although prediabetes is a significant risk factor for type 2 diabetes, lifestyle interventions have been proven effective for slowing the progression from pre to diabetes and are recommended by the NZ Guidelines. Opportunities for promoting public health interventions at the primary care setting require risk assessment in the first instance. We recommend applying primary care EMR data analysis for risk identification (taking into account demographic, physiological, and lifestyle factors), followed by evidence-based management. Feasibility of analysing EMR data for such clinical quality improvement purposes is increasingly recognised, given that EMRs have been widely used in NZ [15], and increasingly used internationally, e.g., in the United States with incentives through Health Information Technology for Economic and Clinical Health Act (the HITECH Act) [16].

There were a few limitations in the study: firstly, we used EMR data from primary care only, and the general practices included in the analysis were a convenience sample that participated in a CVD medication adherence program and had large case load of high-needs population. Hence, the data might not be representative of the whole NZ population. However, the vignette taken in this opportunistic analysis highlighted a

substantial problem, particularly among high-risk populations. This study had limited scope on investigating incidence rates, and did not examine physiological measures beyond HbA1c or other risk factors such as lifestyle of the populations at risk. Future analysis on EMR data could explore potential predictors and confounders of the condition, e.g., body mass index (BMI) or waist-to-hip ratio as suggested by [17]. Also the current analysis did not extend to look at long-term outcomes such as disease progression, treatment or quality of life. We recommend further and more comprehensive research should be undertaken to answer these important questions.

4. Conclusion

Using EMR data routinely collected in the primary care, we identified an alarming incidence rate of prediabetes, especially among the population groups of certain ethnicities. Given the already high prevalence of diabetes in Māori and Pacific groups, this highlights the need to better prevent and manage the disease progressing.

Acknowledgement

The data used in the analysis were collected in the Caring Does Matter (CDM) program funded by the Pacific Grant Fund, which is a fund of the New Zealand Ministry of Health.

References

[1] World Health Organization. Diabetes Geneva: World Health Organization; 2015 [cited 2015 Mar 12]. Available from: http://www.who.int/mediacentre/factsheets/fs312/en/

[2] World Health Organization. Global status report on noncommunicable diseases 2014 Geneva: World Health Organization; 2015 [updated January 2015; cited 2015 Mar 12]. Available from: http://www.who.int/nmh/publications/ncd-status-report-2014/en/

[3] Tabák AG, Herder C, Rathmann W, Brunner EJ, Kivimäki M. Prediabetes: a high-risk state for diabetes development. The Lancet. 2012;379(9833):2279-90.

[4] International Diabetes Federation. IDF Diabetes Atlas: International Diabetes Federation; 2013 [cited 2015 Mar 12]; 6th. Available from: http://www.idf.org/sites/default/files/EN_6E_Atlas_Full_0.pdf

[5] New Zealand Gudelines Group. New Zealand primary care handbook 2012 Wellington: New Zealand Guidelines Group; 2012 [cited 2015 Mar 12]; 3rd. Available from: http://www.health.govt.nz/system/files/documents/publications/nz-primary-care-handbook-2012.pdf

[6] New Zealand Society for the Study of Diabetes. Reporting and interpreting glycated haemoglobin (HbA1c) results/values Dunedin: New Zealand Society for the Study of Diabetes; 2011 [cited 2015 Mar 12]. Available from: http://www.nzssd.org.nz/HbA1c/3.%20HbA1c%20targets%20Sept%202011%20final%20%20doc.pdf

[7] Braatvedt GD, Cundy T, Crooke M, Florkowski C, Mann JI, Lunt H, et al. Understanding the new HbA1c units for the diagnosis of Type 2 diabetes. The New Zealand medical journal. 2012;125(1362):70-80.

[8] Ministry of Health. New Zealand Health Survey: Annual update of key findings 2012/13. Wellington: Ministry of Health; 2013.

[9] Jeong JY, Kim JG, Kim BW, Moon SS, Kim HS, Park KG, et al. Trend analysis of diabetic prevalence and incidence in a rural area of South Korea between 2003-2008. Journal of diabetes investigation. 2010;1(5):184-90.

[10] Sadeghi M, Talaei M, Parvaresh Rizi E, Dianatkhah M, Oveisgharan S, Sarrafzadegan N. Determinants of incident prediabetes and type 2 diabetes in a 7-year cohort in a developing country: The Isfahan Cohort Study. Journal of Diabetes. 2015:n/a-n/a.

[11] Warren J, Gu Y, Kennelly J, editors. The Caring Does Matter (CDM) Initiative: To Improve Cardiovascular Medication Adherence in Pacific People. Proceedings of Health Informatics New Zealand 11th Annual Conference and Exhibition; 2012 Nov 8-9; Rotorua.
[12] Health and Scocial Care Information Centre. Read Codes Leeds, England: Health and Social Care Information Centre; 2015 [cited 2015 Jan 30]. Available from: http://systems.hscic.gov.uk/data/uktc/readcodes
[13] Jo EC, Drury PL. Development of a Virtual Diabetes Register using Information Technology in New Zealand. Healthcare informatics research. 2015;21(1):49-55.
[14] Thornley S, Wright C, Marshall R, Jackson G, Drury PL, Wells S, et al. Can the prevalence of diagnosed diabetes be estimated from linked national health records? The validity of a method applied in New Zealand. Journal of primary health care. 2011;3(4):262-8.
[15] Schoen C, Osborn R, Doty MM, Squires D, Peugh J, Applebaum S. A survey of primary care physicians in eleven countries, 2009: perspectives on care, costs, and experiences. Health Aff (Millwood). 2009;28(6):w1171-83.
[16] Schoen C, Osborn R, Squires D, Doty M, Rasmussen P, Pierson R, et al. A survey of primary care doctors in ten countries shows progress in use of health information technology, less in other areas. Health affairs. 2012;31(12):2805-16.
[17] Dagogo-Jack S, Edeoga C, Ebenibo S, Nyenwe E, Wan J, Pathobiology of Prediabetes in a Biracial Cohort Research G. Lack of racial disparity in incident prediabetes and glycemic progression among black and white offspring of parents with type 2 diabetes: the pathobiology of prediabetes in a biracial cohort (POP-ABC) study. The Journal of clinical endocrinology and metabolism. 2014;99(6):E1078-87.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-87

Automated Classification of Clinical Incident Types

Jaiprakash GUPTA [1], Irena KOPRINSKA and Jon PATRICK
School of Information Technologies, University of Sydney, Australia

Abstract. We consider the task of automatic classification of clinical incident reports using machine learning methods. Our data consists of 5448 clinical incident reports collected from the Incident Information Management System used by 7 hospitals in the state of New South Wales in Australia. We evaluate the performance of four classification algorithms: decision tree, naïve Bayes, multinomial naïve Bayes and support vector machine. We initially consider 13 classes (incident types) that were then reduced to 12, and show that it is possible to build accurate classifiers. The most accurate classifier was the multinomial naïve Bayes achieving accuracy of 80.44% and AUC of 0.91. We also investigate the effect of class labelling by an ordinary clinician and an expert, and show that when the data is labelled by an expert the classification performance of all classifiers improves. We found that again the best classifier was multinomial naïve Bayes achieving accuracy of 81.32% and AUC of 0.97. Our results show that some classes in the Incident Information Management System such as Primary Care are not distinct and their removal can improve performance; some other classes such as Aggression Victim are easier to classify than others such as Behavior and Human Performance. In summary, we show that the classification performance can be improved by expert class labelling of the training data, removing classes that are not well defined and selecting appropriate machine learning classifiers.

Keywords. Clinical incidents, patient safety, machine learning, statistical text classification, decision tree, naïve Bayes, naïve Bayes multinomial, support vector machine

Introduction

In this paper we consider the task of automatic classification of clinical incident reports. Manual coding of free text documents is expensive and inefficient, especially when applied to big datasets. An automated solution that is accurate and consistent is highly desirable [1]. Correct encoding and reporting of incident types is required for patient safety and health system improvement [2, 3]. The architecture of the Incident Information Management System (IIMS) used in Australia is very complex but its core, the Generic Reference Model, has never been tested with statistical rigor [4, 5]. In the state of New South Wales there are over a million clinical incidents documented in IIMS [5]. Our review and those done by others [6] found that research in the area of automated classification of is very contextual. There has been very little research on using statistical text classifiers on IIMS datasets, with only three reported studies [4, 6, and 7]. Ong et al. [7] used binary models for investigating clinical handover, patient identification and risk category instances [8]. In this paper, for the first time, we

[1] Corresponding Author: Jai Gupta; Email: jgup5981@uni.sydney.edu.au.

consider classification of incident reports into multiple classes; in particular, we consider 12-13 clinical incident types. Another contribution of our work is evaluating the performance of more machine learning classifiers than in previous work [7], to determine the best classifier, using a comprehensive set of accuracy measures. We also study the effect of document labelling undertaken by a clinician compared to an expert, on the accuracy of the classification.

1. Method

We used IIMS data collected from January 2004 to December 2008 that contains information about the following 13 Clinical Incident Types (CIT): Aggression Aggressor (AA), Aggression Victim (AV), Blood and Blood Product (BBP), Behavior and Human Performance (BHP), Clinical Management (CM), Documentation (DOC), Fall (FALL), Hospital Associated Infection/infestation (HAI), Medication (MED), Nutrition (NUT), Primary Care (PM), Nutrition (NUT), Primary Care (PC), Pathology Lab (PATH) and Pressure Ulcers (PU). The total number of incidents was 5448, 250 for each category except for categories HAI, NUT, PATH and PC, where the number of documents was 361, 250, 306 and 31, respectively.

We applied four machine learning classifiers available from WEKA [9], an open source data mining software: Decision Trees (DT), Naïve Bayes (NB), Naïve Bayes Multinomial (NBM) and Support Vector Machine with radial basis kernel function (SVM_RBF). We chose them as they represent different machine learning paradigms and are also state-of-the-art classifiers. We compared their performance by computing the following standard accuracy measures: overall accuracy, recall, precision, F1 measure, Area Under the Curve (AUC) and Kappa statistic.

We conducted four experiments. Experiment 1 used 13 CIT, 14 fields of information and 5448 reports; Experiment 2 used 12 CIT (incident type PC was removed), 10 fields and 5417 reports and Experiment 3 used 12 CIT, 10 fields and 1200 clinical incidents (100 reports per CIT). In all these three experiments the incident reports were classified by clinicians. Experiment 4 was the same as Experiment 3 but the incident reports were classified by an expert not a clinician (the first author of the paper who has over 10 years of experience using IIMS). We followed the same experimental methodology as in [5], including the methods for feature extraction, selection and representation.

2. Results

2.1. Experiments 1 and 2

Table 1 presents the accuracy results for Experiment 1 (columns “13 classes”). The two best performing classifiers were SVM_RBF and NBM achieving accuracy of 78.29-79.06% and Kappa statistic of 0.76-0.77.

An examination of the confusion matrix (Table 2) for the least accurately predicted class PC revealed that it is often misclassified as one of the other classes. As the number of instances in this class is small (31), we removed it and conducted the evaluation using 12 classes (see Table 1, columns “12 classes”). This resulted in improved classification performance for all classifiers except for SVM_RBF – its

accuracy declined from 79.06% to 68.89%, in spite of maintaining the same precision (0.79). The most accurate classifier was NBM achieving accuracy of 80.44%, an improvement from 78.29%.

Table 1. Accuracy results of the four classifiers in Experiment 1 (13 CIT, N=5448) and Experiment 2 (12 CIT, N=5417), clinician classified CITs.

Algorithms	**DT**		**NB**		**NBM**		**SVM_RBF**	
CIT	13	12	13	12	13	12	13	12
Accuracy [%]	73.66	75.54	69.71	71.86	78.29	80.44	79.06	68.89
Kappa statistic	0.71	0.73	0.67	0.69	0.76	0.79	0.77	0.66
Precision	0.74	0.74	0.71	0.71	0.79	0.72	0.79	0.79
AUC	0.89	0.89	0.90	0.90	0.96	0.91	0.89	0.89

Table 2. Confusion matrix for class PC. The correctly classified instances are in bold, the rest are misclassifications.

Classified as – Class >		**AA**	**AV**	**BBP**	**BHP**	**CM**	**DOC**	**FALL**	**HAI**	**MED**	**NUT**	**PC**	**PATH**	**PU**
PC	DT	2	0	0	5	1	0	0	0	0	1	2	0	0
	NB	8	2	5	11	11	2	7	2	10	1	3	2	3
	NBM	0	1	1	4	2	1	2	0	2	0	3	0	0
	SVM_RBF	0	0	0	6	5	2	0	0	0	0	3	0	2

Table 3 shows the accuracy results for the most improved classes (BBP and AV) and the least improved class (BHP), when the number of classes was decreased from 13 to 12. The accuracy of the removed class (PC) is also shown for comparison. The highest improvement in recall was achieved by the DT classifier for class AV (from 0.79 to 0.93). The highest improvement in precision was achieved by the SVM_RBF classifier for class BBP (from 0.83 to 0.91). In terms of F1 measure, the highest improvement was achieved by the DT classifier for class AV (from 0.79 to 0.92). The highest improvement in terms of AUC was achieved by the DT classifier (from 0.95 to 0.98), and we note that 0.95 was already a very high accuracy.

2.2. Experiments 3 and 4

In these experiments a balanced set of clinical incident reports is used 100 reports per CIT, for the 12 CIT (N=1200 clinical incidents). In both experiments the 100 reports per class were randomly selected from the set of all available reports. In Experiment 3, the reports were classified by an ordinary clinician and in Experiment 4 they were classified by an expert. The random selection of 100 reports per class was conducted separately for the two experiments.

Table 4 presents the classification results. As we can see the expert classification resulted in an improvement for all classifiers, for all performance measures, except in 4

out of all 16 cases. In 2 of these cases the performance didn't change (Kappa statistic and precision for NB) and in the remaining 2 cases there was a decrease (AUC for NB and SVM_RBF). For example, in terms of accuracy the improvements were: 5% for DT, 1% for NB and NBM and 14% for SVM_RBF. The best results were achieved by NBM and the most improved classifier was SVM_RBF.

Table 3. Comparison between Experiment 1 (13 classes) and Experiment 2 (12 classes), results for the least and most improved classes.

Performance Measures		**Least Improved Classes**			**Most Improved Classes**				**Weighted Average**	
	Class	PC	BHP		BBP		AV			
		13	13	12	13	12	13	12	13	12
Recall	DT	0.07	0.47	0.45	0.80	0.80	0.79	0.93	0.74	0.76
	NB	0.10	0.46	0.48	0.73	0.73	0.74	0.77	0.70	0.72
	NBM	0.10	0.55	0.58	0.80	0.81	0.82	0.84	0.78	0.80
	SVM_RBF	0.10	0.59	0.68	0.84	0.61	0.86	0.80	0.79	0.69
Precision	DT	0.18	0.50	0.50	0.78	0.76	0.85	0.91	0.74	0.76
	NB	0.05	0.49	0.50	0.84	0.78	0.63	0.70	0.71	0.73
	NBM	0.19	0.62	0.64	0.91	0.91	0.67	0.71	0.79	0.81
	SVM_RBF	0.17	0.59	0.38	0.83	0.91	0.89	0.64	0.79	0.75
F measure	DT	0.71	0.66	0.47	0.49	0.78	0.79	0.92	0.74	0.76
	NB	0.06	0.48	0.49	0.78	0.75	0.68	0.73	0.70	0.72
	NBM	0.13	0.59	0.61	0.85	0.86	0.74	0.77	0.78	0.80
	SVM_RBF	0.12	0.59	0.49	0.84	0.73	0.87	0.71	0.79	0.69
AUC	DT	0.60	0.77	0.79	0.89	0.89	0.95	0.98	0.89	0.90
	NB	0.64	0.79	0.80	0.93	0.92	0.90	0.90	0.90	0.90
	NBM	0.80	0.91	0.91	0.97	0.97	0.96	0.96	0.96	0.97
	SVM_RBF	0.55	0.78	0.78	0.91	0.80	0.93	0.87	0.89	0.83

Table 5 shows the results for the most and least improved CITs. The two most improved classes were AV and AA, and the two least improved classes were BHP and BBP. The highest improvement in recall, precision and AUC was achieved by DT for class AV (from 0.33 to 0.87, from 0.38 to 0.81, and from 0.77 to 0.97, respectively). In terms of F1 measure, the highest improvement was achieved by NBM for class AV (from 0.36 to 0.69). For comparison, for the least improved class, BHP, the DT classifier achieved a much smaller improvement (from 0.02 for AUC to 0.11 for recall).

Table 4. Results of the four classifiers in Experiment 3 (12 CIT, N=1200, clinician classified CITs) and Experiment 4 (12 CIT, N=1200, expert classified CITs).

Algorithms	**DT**		**NB**		**NBM**		**SVM_RBF**	
	Expert	Clinician	Expert	Clinician	Expert	Clinician	Expert	Clinician
Accuracy [%]	70.17	65.91	70.08	69.60	81.32	79.58	54.92	41.12
Kappa statistic	0.68	0.63	0.67	0.67	0.80	0.78	0.51	0.33
Precision	0.70	0.66	0.71	0.71	0.81	0.8	0.69	0.63
AUC	0.89	0.85	0.89	0.91	0.97	0.96	0.41	0.66

Table 5. Comparison between Experiment 3 (clinician classified CITs) and Experiment 4 (expert classified CITs) for 12 classes (N=1200).

Performance Measures		**Minimally improved Classes**				**Most improved Classes**				**Weighted Average**	
	Classes	BHP		BBP		AV		AA			
	Classifier	Exp	Cli	Exp	Cli	Exp	Cli	Exp	Cli	Exp	Cli
Recall	DT	0.67	0.56	0.75	0.68	0.87	0.33	0.84	0.35	0.70	0.66
	NB	0.48	0.44	0.76	0.70	0.74	0.54	0.66	0.35	0.71	0.71
	NBM	0.62	0.57	0.89	0.89	0.79	0.40	0.58	0.75	0.81	0.80
	SVM_RBF	0.42	0.37	0.47	0.24	0.74	0.56	0.39	0.35	0.69	0.63
Precision	DT	0.49	0.42	0.75	0.66	0.81	0.38	0.52	0.62	0.70	0.66
	NB	0.49	0.45	0.84	0.76	0.60	0.26	0.67	0.60	0.70	0.70
	NBM	0.64	0.63	0.93	0.86	0.61	0.33	0.75	0.62	0.81	0.80
	SVM_RBF	0.52	0.48	0.96	0.90	0.58	0.42	0.64	0.21	0.55	0.41
F1 measure	DT	0.78	0.73	0.43	0.41	0.75	0.67	0.81	0.79	0.00	0.00
	NB	0.83	0.77	0.46	0.46	0.80	0.73	0.90	0.88	0.00	0.00
	NBM	0.93	0.91	0.99	0.87	0.69	0.36	0.96	0.93	0.79	0.81
	SVM_RBF	0.50	0.25	0.63	0.39	0.59	0.00	0.80	0.69	0.56	0.41
AUC	DT	0.91	0.89	0.91	0.85	0.97	0.77	0.90	0.80	0.89	0.85
	NB	0.90	0.89	0.94	0.93	0.90	0.86	0.89	0.82	0.91	0.90
	NBM	0.95	0.95	0.98	0.97	0.95	0.90	0.95	0.91	0.97	0.96
	SVM_RBF	0.68	0.47	0.62	0.47	0.52	0.50	0.60	0.60	0.61	0.46

3. Discussion

Automatic classification of clinical incident reports into two classes has been successfully tested and reported in [5]. In this paper we considered 12-13 classes and showed that it is possible to build accurate multiclass classifiers of clinical incident

reports using machine learning methods. This is an important step as complex systems such as IIMS cannot be over simplified and require multiclass classification methods.

In particular, our results showed that the NBM classifier (which hasn't been previously applied to IIMS data) was consistently the best performing classifier, obtaining accuracy of 80.44% on clinician-labelled data and 82.32% on expert-labelled data. The second best classifiers were DT and NB, and finally SVM_RBF.

Kappa statistic gives a chance-corrected measure of agreement between the classifications and the true classes, 1indicates a statistically perfect modelling whereas a 0 means every model value was different from the actual value. Kappa statistic was 0.70 and over on NBM classifier. A kappa statistic of 0.70 or higher is generally regarded as good and getting close to statistically perfect model [10] and this was reached when combined data types were used.

An advantage of multiclass classification over binary classification is that it provides more useful insights which classes are difficult and easy to classify, and this knowledge can be used to improve the definition of the classes, in collaboration with clinical experts. We were able to identify class PC as frequently misclassified and showed that its removal improved the classification results. Prompted by the results, we found that class PC is not well defined and not clearly distinguishable from the other classes. Therefore, we recommend that it is removed from the IIMS and that it is recorded in a separate database.

4. Conclusion

In this paper we considered the task of automatic classification of clinical incident reports collected from an incident information management system. We formulated the problem as multiclass text classification and evaluated the performance of several machine learning classifiers. We found that NBM was the most accurate classifier achieving an accuracy of 80.44% on clinician-labelled data 82.32% on expert-labelled data, which are promising results. Our results showed that some classes such as Primary Care are often misclassified as they are not well defined, and we recommend their removal from the incident management system. We also found that expert-labelled training data resulted in better classification performance compared to clinician-labelled data.

References

[1] AHIMA computer assisted coding e-HIM work group. Delving into computer-assisted coding. J AHIMA, 75 (2010), 48A-48H.

[2] D. Pettet and L. Donaldson, Challenging the world: patient safety and health care associated infection. International J Quality in Health Care 18 (2006), 4-6.

[3] K.E. Wood and D.B.Nash, Mandatory state-based error-reporting systems: current and future prospects. Am J Med Qual 20 (2005), 297–303.

[4] W.B. Runciman, S.C.Helps, E.J. Sexton et al. A classification for incidents and accidents in the health-care system. J Qual Clin Pract.18 (1998),199–211.

[5] J. Gupta and J.Patrick Automated validation of patient safety clinical incident classification: macro analysis. Stud Health Technol Inform.(2013)188:52-7.

[6] M.H. Stanfill, M.Williams,S.H. Fenton, R.A.Jenders and W.R.Hersh, A systematic literature review of automated clinical coding and classification systems, J Am Med Inform Assoc. 17 (2010), 646-651. DOI: http://dx.doi.org/10.1136/jamia.2009.001024

[7] M. Ong, F. Magrabi,E. Coiera. Automated categorization of clinical incident reports using statistical text classification. Qual Saf Health Care 19 (2010) 1-7.
[8] M. Ong, F.Magrabi, E.Coiera. Automated identification of extreme-risk events in clinical incident reports. J Am Med Inform Assoc. 19 (2012) 110-8
[9] WEKA http://www.cs.waikato.ac.nz/ml/weka/downloading.html
[10] M. A. Hall. Correlation-based Feature Subset Selection for Machine Learning. Hamilton, New Zealand. 1998.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-94

Model Selection and Variable Aggregation of Australian Hospital Data

Liam HEINIGER [a], Norm GOOD [b,1] and Sankalp KHANNA [b]
[a] *University of Queensland, Brisbane, Australia*
[b] *CSIRO Australian e-Health Research Centre, Brisbane, Australia*

Abstract. Background Hospital administrative data commonly consist of hundreds of variables with many consisting of hundreds, if not thousands, of distinct categories, especially for disease groups. Conventional approaches to develop regression models for prediction either fail completely due to multicollinearity or sparsity issues or take too long and consume too many computer resources. **Methods** We demonstrate how regularisation and variable aggregation techniques such as Elastic Net can overcome some of these problems. Parameter estimates from univariate generalised linear models (GLM) and Elastic Net models were used to aggregate disease groups into a more manageable number and predict the probability of mortality for a given patient. **Results** When employed for variable aggregation and variable selection, Elastic Net models ran at least four times faster than GLMs, though producing a less discriminative model. When applied to final models for predicting hospital mortality, though, both Elastic Net and GLM models demonstrated similar predictive power and efficiently solved an otherwise complex problem. **Conclusion** Elastic Net regularisation and variable aggregation provide an efficient mechanism for solving healthcare modelling problems.

Keywords. HSMR, Model Selection

Introduction

Multivariate statistical analysis, or modelling relationships between multiple variables, is often employed to help demystify the complexity of the health domain. Such analysis can, for example, help researchers and clinicians understand associations between various diseases or account for variation in one disease by a combination of two or more factors contributing to the disease. Most large complex datasets, in particular health data, are plagued by large sets of collinear variables, complex interactions, and categorical variables consisting of hundreds, if not thousands, of levels. This can often lead to unreasonable modelling complexity, confounded relationships, and reduced reliability of modelling outcomes.

An example of such a complex statistical modelling problem is modelling of Hospital Standardised Mortality Ratios (HSMR) [1] from inpatient and emergency presentation administrative hospital datasets. The information from these datasets is used to model

[1]Corresponding Author: Norm Good, CSIRO Australian e-Health Research Centre, Brisbane, Australia; E-mail: Norm Good@csiro.au

and predict the probability of in-hospital mortality for a given patient. These predicted probabilities are then used to calculate HSMR values, generally represented as the number of deaths over the sum of the predicted values for a given hospital over a given period of time. Building HSMR models can lead to several problems with model selection techniques due to the large amounts of data and a great number of (often sparsely populated) levels in variables such as primary diagnosis. It is also common that numerous factors, or variables, employed for the analysis will be multicollinear (i.e. highly correlated), further complicating the analysis.
In this paper, we employ the modelling of HSMR as an example problem to demonstrate how regularisation techniques like Elastic Net [2] can be employed to address the multicollinearity and reduce the number of predictors to a subset of important predictors. We also demonstrate how these regression techniques can be used for variable aggregation, i.e. reducing the high number of categories and sparsity among categorical variables whilst generating adequate models to explain patterns in the dataset. We also discuss how employing both these techniques together can help significantly reduce the complexity of the modelling exercise without reducing its efficacy.

Methods

To demonstrate the benefits of employing regularisation and variable aggregation, we focus on the task of employing admitted inpatient and emergency department presentation data from Australian hospitals over an analysis period of several years to model and predict the probability of mortality for a given patient. Such a model can then be employed to calculate HSMR values as demonstrated in [3]. Since the focus of this manuscript is the discussion of the methodology and not the results, specifics beyond the structure of the data are not discussed.
The inpatient dataset employed comprised demographic information (age, gender, funding etc), clinical information (Disease Related Group, Principal Diagnosis, time in intensive care, length of stay, care type, etc), and limited discharge information (discharge disposition, whether readmitted within 28 days, etc). The emergency presentation dataset provided similar details related to the patient's visit to the Emergency department. The International Classification of Diseases (version ICD-10) was used to represent the primary diagnosis relevant to a hospital admission. Patient comorbidities were represented using the Charlson Comorbidity Index (CCI) [4].
Mortality probability models took the form of a binomial generalised linear model. The models that were explored comprised clinical and demographic variables and their potential interactions. Training sets were randomly sampled from the data, and used for model construction, while a separate test dataset was used for model validation. Receiver Operating Characteristic (ROC) curve analysis was employed to measure the performance of the models, with the c-statistic (or AUC), representing the area under the ROC curve, used as a measure of discrimination and used to compare the performance of the models. Despite the fact that the models were developed using 64-bit version of the *R project for statistical computing*[2] on an *Intel E5-2630 CPU* machine with *2x2.6GHz* processors and *128GB* of RAM, the multicollinearity and high spread of categorical variables re-

[2]http://www.r-project.org/

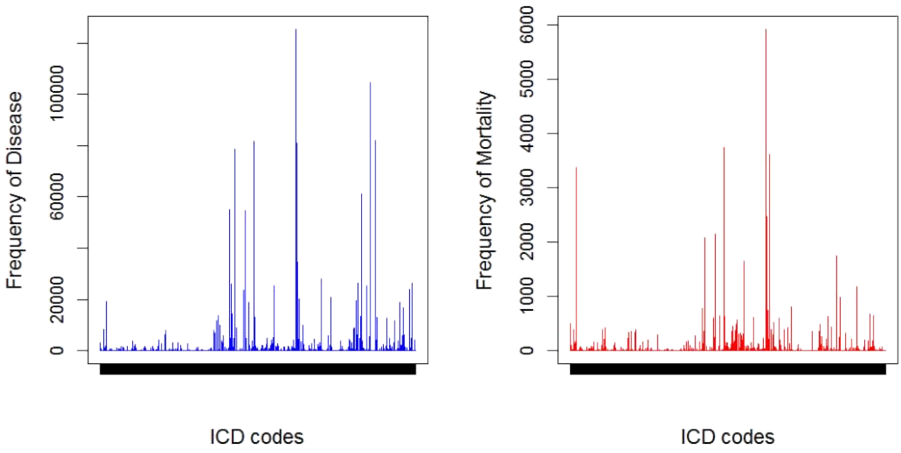

Figure 1. Histograms of all ICD-10 codes in a subset of patients whom were Elective Surgical inpatients

sulted in the above modelling exercise proving to be an infeasible solution requiring an unreasonable amount of time and processing power to compute variable estimates.

To deal with the multicollinearity problem, we employed an Elastic Net model selection technique. The Elastic Net is a regularisation and variable selection method for regression problems. It is similar to lasso [5] and ridge regression [6], however it is much better at dealing with multicollinearity problems. The main efficiency gained from using the Elastic Net is in forcing the parameter estimates for non or weakly expressed variables to zero (termed "shrinkage"). The effect of this is a combination of averaging the highly correlated terms and reducing the sparseness of solutions.

Ten-fold cross validation was employed to select tuning parameters within one standard deviation from the minimum deviance. These were employed along with simple conditional probability plots to determine variables which showed strong correlations. These were removed from the model selection procedure to hasten the process.

Given that the ICD-10 codes found in the primary diagnosis field had over a thousand distinct values in our dataset, we employed variable aggregation to group diseases with similar parameter estimates in the model. Univariate modelling of the effect of each disease was done to determine the parameter estimates. As a pre-aggregation step, diseases where all patients died were allocated into the highest risk group. Conversely, diseases where all patients survived were allocated into the lowest risk group. The parameter estimates for the remaining levels were then determined using both binomial generalised linear modelling, and 10-fold cross validation Elastic Net modelling (with a tuning parameter of 1 standard deviation away from the middle). Parameter estimates were then aggregated into natural bins using the Jenks natural breaks algorithm [7]. The implementations of Lasoo and Elastic Net in the *glmnet*[3] package of the *R* environment were employed for the analysis.

[3] http://cran.r-project.org/web/packages/glmnet/index.html

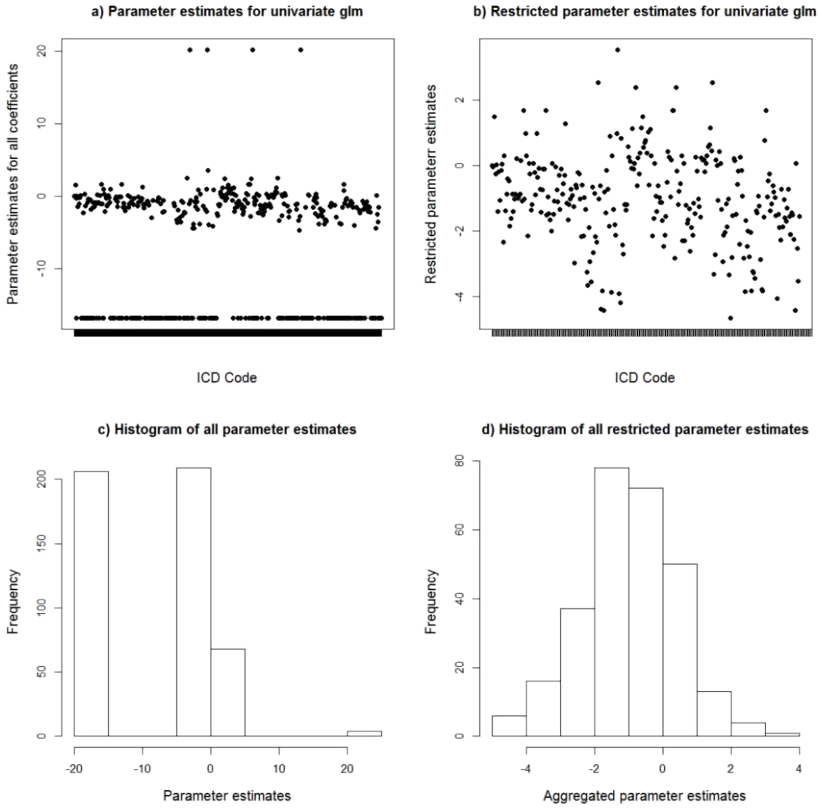

Figure 2. Steps involved in the aggregation of ICD codes from a univariate univariate binomial generalised linear model

Results

Figure 1 shows the frequency distribution of the primary diagnosis of patients admitted through the ED (listed as ICD-10 codes) and the deaths associated with them. Initial models failed to converge (despite a time out period of 96 hours) due to the high number of sparse principal diagnosis levels and their interaction with other variables. Aggregating the primary diagnosis into two categories, $all - death$ and $all - survival$, made the process more efficient requiring parameter estimates only for those ICD-10 codes that could not be aggregated into one of these two groups. As a variable, aggregated primary diagnosis now explained a greater deal of the variability in the data. This pre-aggregation step was however, most effective for smaller datasets given that fewer diseases resulted in $all - death$ or $all - survival$ in larger data sets.

Figures 2 and 3 illustrate the results of applying the GLM and Elastic Net algorithms for variable aggregation respectively. Figures 2a and 2c show the parameter estimates for all individual ICD-10 codes and their associated histogram respectively. Figures 2b and 2d show the spread of the remaining parameter estimates and the associated histogram once the very low ($all - survival$) and very high ($all - death$) estimates were filtered out, removing the skew caused by their effect. Univariate models for principal diagnosis

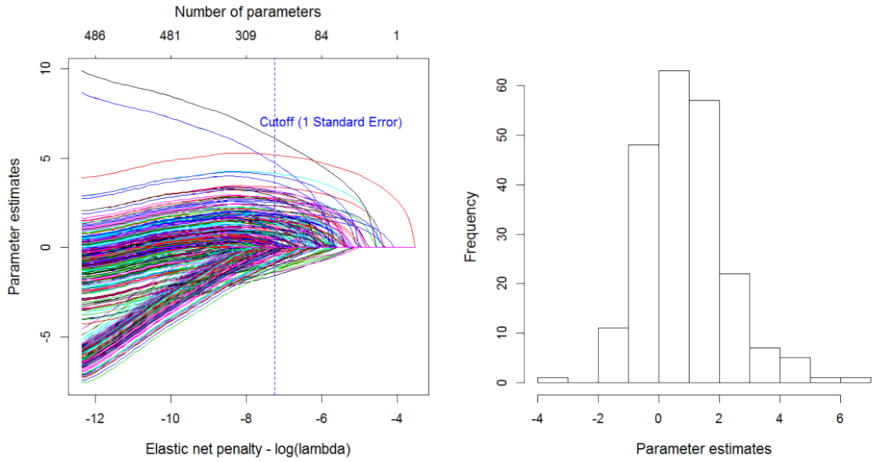

Figure 3. Steps involved in the aggregation of ICD codes from a Elastic Net

on this filtered (i.e. $all - death$ and $all - survival$ removed) dataset returned parameter estimates for each ICD code. The standard binomial GLM produced an AUC of 0.75, whereas the Elastic Net model completed in less than a quarter of the time and produced an AUC of 0.65. Both models however produced similar patterns with a similar number of aggregate levels, range of values, and number in each level. The parameter estimates were then aggregated into natural bins using the Jenks natural breaks algorithm. One of the desirable features of Elastic Net parameter estimation was shrinkage, i.e. the forcing of some non-significant/categorical variables towards zero. Using the Elastic Net method this resulted in many more ICD-10 codes being placed in the $all - survival$ level.
When the calculated parameter estimates were placed back into a larger model with the other variables and second order interactions, the GLM and Elastic Net techniques used had little affect on the time taken or the performance of the final produced models, with either type of aggregation producing ROCs with and AUC value of approximately 0.85.

Discussion

While initial efforts to model and predict the probability of mortality for a given patient failed due to multicollinearity and the large spread of categorical variables, employing regularisation and variable aggregation techniques resulted in producing models that could be used to successfully generate HSMR values for the data.
Comparing initial results from the Elastic Net and GLM selection methods, parameters estimations by the GLM expectedly outperformed the Elastic Net models, though the latter were significantly more efficient to run. The difference in parameter estimation can likely be attributed to the modelling design followed by each algorithm. The Elastic Net initially allocated parameters which had the most effect. These variables are likely to have been the diseases which result in extremely high or low probabilities of death, compared to the diseases which have little effect. For example, diseases which have approximately 50% of patients resulting in death are unlikely to have a significantly large magnitude for the coefficients in the Elastic Net model. This leads to the Elastic Net excluding

them, and instead focussing on diseases with larger effect. Conversely the GLM model only looked for diseases producing probabilities of death which were neither too close to zero or one. The diseases which result in mostly death, or induce a high probability of death, were aggregated into one variable; similarly the disease unlikely to result in death or produce probability of death close to zero were aggregated into one variable. Thus the minutiae of the model is seen in the variables which are not producing the largest effects on the model. These variables were then aggregated to a natural number of bins. While this difference was observed in the univariate modelling, employing these parameter estimates back into a larger model yielded similar levels of model performance, with both GLM and Elastic Net methods returning an AUC of 0.85. This suggests that the method chosen for aggregating variables is less significant that the act of aggregation itself, a significant finding since employing techniques like Elastic Net regularisation allows for more time-efficient and computation-efficient modelling efforts.

As demonstrated here, both regularisation and variable aggregation may be implemented together in order to make the model selection process more feasible. Once a new variable is created it can be aggregated and added to a much larger model. With the resulting fewer number of levels to contend with, there are less restrictions on the techniques that can be efficiently employed on the model. This methodology can also be applied to simplify model building for other health and non-health problems that employ large volumes of complex and highly collinear data. It is also important to understand limitations when working with data sources like the ones employed here. For example, consistency, data semantics, and coding practices must be considered when working with data entered by multiple staff members at various hospital services.

Conclusion

We have shown that where GLM models fail due to multicollinearity and high number of levels in categorical variables, techniques like Elastic Net regularisation and variable aggregation can provide efficient mechanisms for dealing with the complexity that often confounds health data modelling and solving the problems at hand.

References

[1] Canadian Institute for Health Information (CIHI). HSMR: A New Approach for Measuring Hospital Mortality Trends in Canada, 2007.

[2] T. Hastie, R. Tribshirani, and J. Friedman. *The Elements of Statistical Learning: Data Mining, Inference, and Prediction*. Springer, second edition, February 2009.

[3] C.M. Sullivan, A. Staib, J. Flores, L. Aggarwal, A. Scanlon, J.H. Martin, and I.A. Scott. Aiming to be NEAT: safely improving and sustaining access to emergency care in a tertiary referral hospital. *Australian Health Review*, 38(5):564–574, 2014.

[4] M.E. Charlson, P. Pompei, K.L. Ales, and C.R. MacKenzie. A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. *Journal of Chronic Diseases*, 40(5):373–83, 1987.

[5] R. Tibshirani. Regression shrinkage and selection via the lasso. *Journal of the Royal Statistical Society, Series B*, 58:267–88, 1996.

[6] S. Le Cessie and J.C. Van Houwelingen. Ridge estimators in logistic regression. *Applied statistics*, pages 191–201, 1992.

[7] Jenks G.F. The data model concept in statistical mapping. *International Yearbook of Cartography*, 7:186–90, 1967.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-100

The Personally Controlled Electronic Health Record (PCEHR) for Adults with Severe Communication Impairments: Findings of Pilot Research

Bronwyn HEMSLEY[a,1], Andrew GEORGIOU[b], Susan BALANDIN[c], Rob CARTER[c], Sophie HILL[d], Isabel HIGGINS[e], Paulette VAN VLIET[f] and Shaun McCARTHY[g]
[a] *School of Humanities and Social Sciences, Faculty of Education and Arts, The University of Newcastle, Australia*
[b] *Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia*
[c] *School of Health and Social Development, Faculty of Health, Deakin University, Melbourne, Australia*
[d] *School of Psychology and Public Health, La Trobe University, Melbourne, Australia*
[e] *School of Nursing and Midwifery, The University of Newcastle, Australia*
[f] *School of Health Sciences, Faculty of Health and Medicine, The University of Newcastle, Australia*
[g] *Newcastle Law School, Faculty of Business and Law, The University of Newcastle, Australia*

Abstract. To date, there is little information in the literature to guide the provision of supports for using the Personally Controlled Electronic Health Record (PCEHR) in populations with severe communication impairments associated with a range of disabilities. In this paper we will (a) outline the rationale for use of PCEHR in these populations by providing an overview of relevant research to date, and (b) present results of three integrated pilot studies aiming to investigate the barriers to and facilitators for PCEHR use by people with severe communication impairments and their service providers. Finally, we will present directions for future research on use of PCEHR by people with severe communication impairments.

Keywords. PCEHR, severe communication impairment, disability supports

[1] Corresponding Author: Associate Professor Bronwyn Hemsley, Faculty of Education and Art, The University of Newcastle, University Drive Callaghan NSW 2308, Australia; E-mail: bronwyn.hemsley@newcastle.edu.au

Introduction

An estimated 6.1% (~1.4M) of the Australian population have severe or profound limitations in the core activities of communication, mobility and/or self-care [1, 2]. People with severe communication impairments include those with acquired brain injury (e.g., stroke, traumatic brain injury) neurodegenerative disorders (e.g., Parkinson's disease) and developmental disabilities (e.g., cerebral palsy, intellectual disability, autism). In this heterogeneous group, 70% report having four or more long-term health conditions [3]; and up to 80%, have severe communication impairments, including 25% who are non-verbal [4]. They have significantly higher rates of health service utilisation than the general population [5,6] and health service utilisations increase as this group experiences age-related illness and functional decline [7]. This group often relies on family carers or paid carers for support to access health care [8-14]. They experience problems with early hospital discharge and unplanned readmission [6], have a three-fold increased risk of patient safety incidents in hospital [12,15] and are at risk of preventable harm and/or premature death related to poor communication [16 - 19]. There is now substantial evidence that problems with healthcare for patients with severe communication impairments relate to the inadequate exchange of health information [8-14,16]. These patients struggle to convey their health history and symptoms, and in healthcare episodes carers are unable to pass on all relevant health information in the limited time available [8-14, 16]. When admitted to hospital, people with severe communication impairments often take large folders of written information [12]. This information is rarely used by hospital staff who do not have time to 'sift through' a plethora of documents for information on medications, health history, and care planning [17]. Poor health information exchange and follow-up leads to a cascade of errors and, at the most extreme, premature death [19]. To date, there has been no attempt to evaluate ways to improve the exchange of health information for this vulnerable group of people.

The Personally Controlled Electronic Health Record (PCEHR) is "an electronic record for a patient that contains a summary of their health information from all their participating healthcare providers" [23]. It provides a timely means to rectify the problems associated with the poor exchange of healthcare information for people with severe communication impairments. Introduced in Australia in 2012, the main purpose of the PCEHR is to improve the quality, safety and efficiency of patient care [20-22]. Health benefits to individuals using PCEHR are expected to occur when: (a) patients and their healthcare providers are engaged in updating, uploading, sharing, and reading information in the record; (b) with regular use, the record builds up a picture of 'health events' for an individual; and (c) the information in PCEHR is referenced at critical points such as admission to hospital, discharge from hospital, and change of health or disability service providers [23]. Using PCEHR will increase patients' engagement in their own healthcare, potentially resulting in cost-benefits to the health system [24, 25]. Although the PCEHR presents an opportunity to improve health information exchange for people with severe communication impairment and associated poor health literacy [26], it also presents practical challenges for this group. Without appropriate support it is likely that people with severe communication impairment will be functionally excluded from this promising national e-health initiative [16, 27]. Disability and health services will need to support this population to use the PCEHR; but there is no evidence to guide them in how to do this. The proposed research will address this gap in knowledge.

1. Establishing the Rationale for PCEHR and Its Potential Benefits for People with Severe Communication Impairments

In 2014 we were invited to conduct a metasynthesis review of research investigating the communication and care experiences of adults with severe communication impairments in hospital [14]. This revealed a strong rationale for shared health information to replace the ineffectual written folders patients/carers take to hospital, and the need to address substantial problems with care and safety. Our subsequent review of PCEHR literature in 2015 found only one study investigating the use of electronic medical records (not PCEHR) which related to making information about systems more accessible to adults with intellectual disabilities [16], a sub group of our target population. The National eHealth Transition Authority (NeHTA) publications have provided important information on the scale of use for PCEHR since its launch in July 2012. To date, 10,721 medical practitioners, 7,645 healthcare providers, and just over 2 million Australians have registered to use PCEHR [20, 23]. GP practices receive some support from Medicare Local e-health teams to use the system (in future, Primary Health Networks). However, we located no disability-specific information to guide disability and health services on the nature, configuration, or amount of support needed to implement PCEHR with any group, including people with severe communication impairments.

2. Pilot Studies on PCEHR for Adults with Severe Communication Impairments

In 2014 we obtained ethical approval of the Human Research Ethics Committee at The University of Newcastle and the organisations assisting with recruitment, to conduct this research on use of the PCEHR with people who have severe communication impairments associated with a range of chronic disabling health conditions including: cerebral palsy, aphasia following stroke, intellectual disability, and traumatic brain injury. The aim of the studies was to investigate people's views and experiences of PCEHR, so as to identify barriers and facilitators to using PCEHR to inform future policy direction and future research.

2.1. A Sociotechnical Case Study (Observation) of Home Health Record Use

This sociotechnical case study of a young adult (aged under 25) with severe cerebral palsy and severe communication impairments involved an interview, an observation of her use and access to her own health records at home, and an examination of her home health informatics (storage method and document types). She used a wheelchair for mobility and having no speech used a speech-generating device to communicate, by use of a wheelchair mounted switching system. Her health information was stored loosely at home as hard copy documents in an expandable file, and in soft copy on her personal computer in the 'documents' folder or on 'email'. She required full assistance from a carer to access the health documents in the expandable file (i.e., retrieval from under her desk, open, search through, find). In contrast, she accessed the computer and Internet independently using assistive technologies, and could retrieve information that health professionals had sent to her by email. However, her health information was not stored or organised systematically; there was some ad-hoc duplication between electronic and hard copy information; and no cross-referencing. This case study

suggested that the PCEHR could benefit individuals with severe communication impairments, but that a range of supports may be needed to (a) organise and prepare information for upload to the PCEHR in a systematic way [28], and (b) integrate hard and soft copy documents (on the home computer) with documents in the PCEHR.

2.2. Survey of Adults with Severe Communication Impairments on Use of PCEHR

In 2014, we surveyed 12 adults with diverse severe communication impairments (after stroke, cerebral palsy, brain injury) about using PCEHR, including 9 by face-to-face interviews and three by online survey. All participants lacked confidence communicating with unfamiliar healthcare providers and thought the PCEHR would help them by improved 'storing' and 'sharing' of health information that was important to them. Only one of the 12 had registered for PCEHR and all wanted further information from disability service providers. This suggests that supports are needed for this group to commence PCEHR use and upload documents. The participant who had registered for PCEHR considered it had been beneficial and all participants expected to benefit by using PCEHR. As one said: "*It is so tiring to continually explain my history and progress. Every meeting with a new health professional requires a lot of work for them to understand*." Further information is needed to determine whether the investment of time and effort by people with severe communication impairments and their supporters in using PCEHR will see improved health information exchange when people with these disabilities meet with health professionals [6,9-13].

2.3. Focus Groups Discuss the PCEHR

In 2015, we held two focus groups to discuss barriers to and facilitators for PCEHR in people with severe communication impairments. Each focus group was 1 hour long and held at each participant's workplace. The groups were audiotaped and transcribed verbatim with identifying information removed, and analysed for content themes. Participants in our pilot study were care workers in supported accommodation (n = 9) and allied health clinicians (n = 5) supporting adults with severe communication impairments. Further focus groups are underway in March 2015 to capture other key stakeholder groups (parents, medical staff, nurses). Overall, the focus group discussions reflected that direct support workers and allied health professionals have a keen interest in PCEHR, perceiving it to be "wonderful", and "a huge benefit" to people with severe communication impairments. However, despite seeing themselves as pivotal in prompting GPs to use their clients' PCEHRs, they had no personal experience of using PCEHR themselves. For example, they were unclear about who would give consent to opt in or out of PCEHR when a client lacked capacity, and about who gave consent for uploading new documents (e.g., a Shared Health Summary). Allied health professionals were also unsure how use of the PCEHR would facilitate collaborative engagement across the disciplines and saw the role of GP as pivotal in this regard. They also acknowledged that PCEHR might support improved health information exchange for people with disabilities who see new healthcare providers in busy GP practices.

3. Directions for Future Research

As governments seek to predict costs relating to the physical wellbeing of adults with disabilities, the allocation of funding for carers and disability and health services to support people with severe communication impairments in using PCEHR has been overlooked. The findings of these pilot studies are timely, as from 2016, the demand for effective exchange of health information will increase as disability service provision in Australia transitions from highly regulated government to non-government providers through individual funding packages within the National Disability Insurance Scheme (NDIS). Disability support worker time will be tied to provision of funds for support in the home. There is an urgent ethical imperative to focus research efforts on PCEHR use in populations with severe communication impairments who have a three-fold increased risk of adverse events, and are at risk of being excluded from use of the PCEHR system unless there are adequate supports from disability service providers and carers. Further research is needed to inform policies and practices that will help to ensure the inclusion of people with many types of disabilities in one of Australia's most significant national public health ICT initiatives. This information is urgently needed as new policies and updated legislation for PCEHR are formed, to ensure that 'adoption' is followed by use and not by the 'abandonment' or dis-use associated with problems either with the process, people involved, or the PCEHR technology.

Further research is needed to determine the configuration, types, timing, and amount of support needed for adults with severe communication impairments to use the PCEHR, by investigating: (a) Factors affecting successful use of PCEHR by people with severe communication impairments, their families, support workers, and health service providers; (b) Risks and benefits of PCEHR use for people with severe communication impairments; (c) People, teams, and processes needed to deliver supports for functional use of PCEHR; (d) Costs and potential cost offsets of supporting the target population to use PCEHR; and (e) An exploratory economic appraisal that draws together findings of (a)-(d) to model potential cost-effectiveness.

4. Conclusion

In conclusion, the results of our three pilot studies show that PCEHR usage is not yet integrated into organisational policies in supported accommodation settings. People with severe communication impairments, direct support workers, and allied health clinicians are uncertain about how PCEHR integrates with existing paper records in terms of duplication, overlap, or replacement. They perceive use of PCEHR to be beneficial but are unsure whether PCEHR use will replace the large amount of written material in folders taken to appointments for patients with complex conditions. Consequently, it is essential to understand how both paper and PCEHR records integrate in the home so that implementation of PCEHR is not problematic [28]. Participants in our pilot studies were unsure whether healthcare providers would invest the extra time required to use PCEHR with patients who, because of their communication impairments already require long consultations. They feared they would be refused access to GP practices for this reason. Thus, it is vital to match the 'time cost' of using PCEHR with evidence of 'time benefit' and 'health benefit'; the benefits of PCEHR in reducing adverse events associated with poor information exchange may only be seen if time efficiency is evident. Given the pivotal part carers

play in supporting information exchange, their lack of clarity about their roles in relation to PCEHR poses a threat to its use and potentially impedes its long term benefit.

References

[1] ABS, *Disability, Ageing and Carers, Australia: Summary of Findings, 2012*. Australian Bureau of Statistics. Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0 2013.

[2] ABS, *Australia Population Clock. ABS Aspects of Disability and Health in Australia, 2007-2008.* Australian Bureau of Statistics, Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/Products/4367.0~2007-2008~Main+Features~Selected+Long-Term+Health+Conditions?OpenDocument

[3] Access Economics. *The economic impact of cerebral palsy in Australia in 2007.* Report by Access Economics for Cerebral Palsy Australia, 2008.

[4] N.L. Young, et al., Youth and young adults with cerebral palsy: Their use of physician and hospital services. *Arch of Phys Med and Rehab, 88,* (2007), 696-702.

[5] R.A. Wallace, & H. Beange, On the need for a specialist service within the generic hospital setting for the adult patient with intellectual disability and physical health problems. *Journal of Intellectual & Developmental Disability, 33*, (2008), 354–361.

[6] D. Strauss, K. Ojdana, R. Shavelle, & L. Rosenbloom, Decline in function and life expectancy of older persons with cerebral palsy. *NeuroRehabilitation,* 19 (2004), 69-78.

[7] S. Balandin, B. Hemsley, J. Sigafoos, & V. Green, Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs. *Applied Nursing Research,* 20 (2007), 56-62.

[8] B. Hemsley, S. Balandin, & L. Worrall, Nursing the patient with complex communication needs: Time as a barrier ... *Journal of Advanced Nursing,* **16** (2012)*,* 116–126.

[9] B. Hemsley, S. Balandin, & L. Worrall, The 'Big 5' and Beyond: Nurses, Paid Carers, and Adults with Developmental Disability Discuss Communication Needs in Hospital. *Applied Nursing Research,* 24 (2011a), e51-e58.

[10] B. Hemsley, S. Balandin, & L.Worrall, Nursing the patient with developmental disability in hospital: The role of paid carers. *Qualitative Health Research,* 21 (2011b), 1632-42.

[11] B. Hemsley, M. Werninck, & L. Worrall, "That really shouldn't have happened": People with aphasia and their spouses narrate adverse events in hospital *Aphasiology.* 27 (2013c), 706-722.

[12] B. Hemsley, S. Balandin, & L. Togher, Professionals' views on the roles and needs of family carers of adults with cerebral palsy and complex communication needs in hospital. *Journal of Intellectual & Developmental Disability,* 33 (2008b), 127-136.

[13] B. Hemsley & S. Balandin, A metasynthesis of patient-provider communication in hospital for patients with severe communication disabilities: informing new translational research. *AAC* 30 (2014), 329-43.

[14] G. Bartlett, R. Blais, R. Tamblyn, R.J. Clermont, & B. MacGibbon, Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *CMAJ,* 178 (2008)155-162.

[15] K. Van Dooren, N. Lennox, & M. Stewart, Improving access to electronic health records for people with intellectual disability ... *Aust Journ of Primary Health,* 19 (2013), 336-42.

[16] D.J. Sands, & M.L Wehmeyer, *Self-determination across the lifespan: Independence and choice for people with disabilities.* Paul H. Brookes Baltimore, 1996.

[17] NSW Ombudsman, *Report on reviewable deaths.* The NSW Government. 2011, 2013.

[18] Scottish Govt, The keys to life: Improving quality of life for people with learning disabilities. Retrieved from: www.scotland.gov.uk/Publications/2013/06/1123 2013.

[19] Y. Pappas, & J. Car, Emerging technologies for health communication. In *The Knowledgeable Patient: Communication and Participation in Health.* Sophie J. Hill. A Cochrane Handbook: Wiley Blackwell Melbourne, 2011.

[20] AHMAC, *Terms of Reference: Priority issues of national significance.* Australian Health Ministers' Advisory Council. Available at http://www.ahmac.gov.au/site/home.aspx 2014.

[21] A. Hordern, A. Georgiou, S. Whetton, & M. Prgomet, Consumer e-health: An overview of research evidence and implications for future policy. *Health Information Management Journal,* 40 (2011), 6-14.

[22] NeHTA, *National e-health Transition Authority.* The Australian Government, Department of Ageing and Disability. [Online website] http://www.nehta.gov.au/ Accessed 2014.

[23] DOHA Department of Health and Ageing, *National e-Health Conference Report Summary of themes arising from National e-Health Conference workshops and stakeholder engagement during July to December 2010*. Aust Govt Dept of Health & Ageing. Deloitte. 2011.

[24] J.H. Hibbard, J. Greene, & V. Overton, Patients with lower activation associated with higher costs ... *Health Affairs.* 32(2) (2013), 216-222.
[25] S. Hill, *The Knowledgeable Patient: Communication and Participation in Health. A Cochrane Handbook*. Wiley-Blackwell: London, 2011.
[26] A. Georgiou et al., Impact of computerised physician order entry systems on pathology services: A systematic review. *Int. J. of Med Inform,* 76 (2007) 514-29.
[27] J. Asha, et al., Some unintended consequences of information technology in health care: The nature of patient care information system-related errors. *Journ Amer Med Inform Assoc*„ 11 (2004) 104-112.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-107

Measuring Data Quality Through a Source Data Verification Audit in a Clinical Research Setting

Lauren HOUSTON, Yasmine PROBST and Allison HUMPHRIES
School of Medicine, Faculty of Science, Medicine and Health, University of Wollongong, Australia

Abstract. Health data has long been scrutinised in relation to data quality and integrity problems. Currently, no internationally accepted or "gold standard" method exists measuring data quality and error rates within datasets. We conducted a source data verification (SDV) audit on a prospective clinical trial dataset. An audit plan was applied to conduct 100% manual verification checks on a 10% random sample of participant files. A quality assurance rule was developed, whereby if >5% of data variables were incorrect a second 10% random sample would be extracted from the trial data set. Error was coded: correct, incorrect (valid or invalid), not recorded or not entered. Audit-1 had a total error of 33% and audit-2 36%. The physiological section was the only audit section to have <5% error. Data not recorded to case report forms had the greatest impact on error calculations. A significant association (p=0.00) was found between audit-1 and audit-2 and whether or not data was deemed correct or incorrect. Our study developed a straightforward method to perform a SDV audit. An audit rule was identified and error coding was implemented. Findings demonstrate that monitoring data quality by a SDV audit can identify data quality and integrity issues within clinical research settings allowing quality improvement to be made. The authors suggest this approach be implemented for future research.

Keywords. Source data verification, data quality, quality assurance, clinical trial

Introduction

High quality data and effective data evaluation are crucial within clinical research as conclusions and recommendations rely largely on the outcomes of data. It is estimated an average of 976 errors (~10%) per 10 000 data points exist from transfer of source data to electronic data records [1,2]. Health data has long been scrutinised in relation to data quality and integrity problems [3,4]. To ensure data quality is an integral component of clinical trials best practice recommends personnel training, standard operating procedures (SOPs), and data monitoring are required to avoid scientific misconduct and assure compliance with the International Conference on Harmonisation (ICH) Good Clinical Practice (GCP) guidelines [5].

Currently no internationally accepted or "gold standard" method exists to measure data quality and error rates within datasets. Dissimilarities between methods make it difficult to determine "acceptable" data quality. Data entry errors may introduce bias risking misleading and/or false results [2,6]. Multiple issues such as error type, extent and variables where errors are found, play an important role in the statistical analyses

in determining data quality [7]. Through the use of routine verification checks, transcription errors can be detected [8].

Auditing is a recognised method used for centuries to assess and develop the quality of products, services and information [9-11]. An auditor's role is to validate data collected on source documents against data entered into electronic records and/or databases. Medical audits are employed to detect and evaluate patient care, services and documented discrepancies [12,13]. Quality assurance audits within clinical settings are an extensively used process recognised to ensure high quality data is produced [1,2,7,14-16]. Many organisations collect and analyse data for the benefit of their own research for quality control and SOPs. Unpublished audit methods and their subsequent results leave a gap within the published literature.

Source data verification (SDV) is the process of comparing source data (original or certified copy) documents to data recorded or entered to a case report form (CRF), electronic record or database. Data integrity can be ensured through different data monitoring techniques, including logic, consistency and range checks, which are useful for determining major errors that are "out-of-the-ordinary". SDV is considered a more accurate method, because it identifies all major and minor errors. Minor errors may seem insignificant, however, consistent minor errors add up and potentially lead to low quality data. Therefore, the aim of this research was to monitor data quality through the use of SDV audits to ensure data integrity within a clinical research setting.

1. Methods

1.1. Planning and Procedure of Data Audit

A SDV audit was performed on baseline data of a prospective clinical trial dataset to determine data quality. Audits occurred between September 2014 and February 2015 at the University of Wollongong and the Illawarra Health and Medical Research Institute (IHMRI). One auditor conducted the audit to ensure consistency. Consensus with the research team on points of uncertainty was conducted prior to commencing.

Paper, handwritten CRFs were used as the source document to collect and store participant information during trial consultations. A team of five clinical Accredited Practising Dietitians transcribed data from CRFs into an electronic spreadsheet record (ESR). To limit bias the SDV audit was blinded from the participating clinical dietitians. A pre-test, post-test style of audit was applied across this research related to a quality improvement framework.

An audit plan was applied to conduct 100% manual verification checks on a 10% random sample of participant files. Verification of original source documents was conducted to determine data quality [17]. During audits, comparison between source documents to data listings entered into the ESR were made. A quality assurance rule was developed, whereby if >5% of data variables were incorrect a second 10% random sample (excluding files already sampled) would be extracted from the data set. A researcher independent of the SDV extracted a 10% random sample of enrolled study participants using SPSS software (version 22 2013, IBM Australia, Lane Cove, NSW, Australia). This approach was based on a monitoring plan by the Acute Respiratory Distress Syndrome (ARDS) network, a National Institute of Health-sponsored clinical trial [1], where a 10% random sample of participants were extracted for review to confirm eligibility and validation of all erroneous data point incidents.

For audit-1 conducted on 1st October 2014, 21 files containing CRFs were extracted from filing cabinets and scanned. A snapshot of the data was taken the same day CRFs were scanned to ensure no changes were made to the ESR during the audit period reducing the risk of introduced bias. The audit was segmented into three relevant sections: anthropometric, physiological and medication data. Sections were determined in relation to the relevant source documents and time-points used for data collection. Each individual data point recorded in the CRF of the above sections was considered. Audit outcomes were coded and recorded into a separate ESR for analysis. Due to audit-1 findings (>5% error rate) in two of three sections, audit-2 was completed on anthropometric and medication data only. Audit-2 commenced on 15th December 2014 and the same procedure for audit-1 was applied. Participants included in audit-1 were excluded from audit-2. Recommendations for continuous quality improvement (CQI) within the context of each dataset were made to ensure future data integrity during the trial.

1.2. Error Classification

During the audit process, data points were categorised using standard audit codes derived from the European Organisation for the Research and Treatment of Cancer (EORTC) [18]. Audited data was coded: Correct (code 1) – Data values entered to the ESR match the values recorded on CRF; Valid incorrect (code 2) – Minor error discrepancies where data had been transcribed incorrectly but had no direct impact on the studies outcome. E.g. values incorrectly rounded to the nearest integer, values entered incorrectly which fell within a predetermined range or incorrectly spelt medications; Invalid incorrect (code 3) – Major errors discrepancies were data that had been transcribed incorrectly that the auditor considered clinically significant. E.g. Missing documents or values entered incorrectly which fell outside a predetermined range; Not recorded (code 4) – Data not recorded on CRF but values exist in ESR; Not entered (code 5) – Data recorded on CRF however had been missed and left blank when entered to ESR.

1.3. Statistical Analysis

To examine data quality and integrity, the total error rate was calculated by dividing erroneous data points (code 2,3,4) by total data points (code 1,2,3,4). Data not entered was excluded from the error calculation, as data not entered was not deemed incorrect. Chi square analyses were used to examine any potential associations between audit-1 and audit-2 and whether data was correct or incorrect.

Data was analysed using SPSS (version 22) statistical analysis software. Statistical significance was set at $p<0.05$. This study was approved by the University of Wollongong Human Research Ethics Committee.

2. Results

A total of 42 randomly selected participant CRFs were extracted for audit-1 (n=21) and audit-2 (n=21). A total of 1505 data points were audited, 958 correct, 20 valid incorrect, 55 invalid incorrect, 260 not recorded and 212 not entered. Of the 212 data points not entered, 44% were from the anthropometric, 1% physiological and 55% medications

data sections of the two audits. Both audit-1 and 2, not recorded data had the greatest contribution to total error rate, 33% and 44%, respectively. Table 1 shows the number of variables audited at audit-1 and 2 and error rate for each section.

Table 1. Audited sections and the percent of erroneous data during audit-1 and 2 for each section.

	Audit-1			Audit-2		
Audit section	**N[a]**	**N_{Err}[b]**	**% Err[c]**	**N**	**N_{err}**	**%Err**
Anthropometric	275	13	6	409	46	13
Physiological[d]	341	0	0	-	-	-
Medicines	204	112	75	276	164	77
Total	640	125	17	685	210	36

Err: Error
[a] Count of data points (N) (code 1,2,3,4,5)
[b] Count of data erroneous data (Nerr) (code 2,3,4)
[c] Percent of erroneous data (code 2,3,4 divided by code 1,2,3,4,)
[d] Physiological audit section did not complete audit-2 due to QA rule (<5% error rate from audit-1)

Error rates ranged from 0-77% within the three audited sections. All audited data records within the physiological section were correct, therefore, the error was <5%, a second audit was not deemed necessary. Anthropometric data error more than doubled, increasing by 7% and medications data error increased by 2%. The medications section had the largest error >75%. Total error more than doubled (17% versus 36%) when comparing audits. Audit-1 and 2 had similar error rates when the physiological data section was excluded, with 33% and 36% error rate, respectively. Exclusion of physiological data from audit-1 increased overall error by 16%.

Chi squared analysis results found significant association between audit-1 and audit-2 and whether or not data was correct or incorrect: $\chi 2$ (4, 1293) = 672.405, p = 0.00. The proportion of correct audit-1 data was significantly related to the proportion of correct audit-2 data. According to these results, 74% of data was deemed correct and 26% was deemed incorrect when combing the results of audit-1 and audit-2.

3. Discussion

Limited published literature exists on the method used for SDV audits and the success of detecting systematic and random errors. Our study developed and applied a straightforward method to perform a SDV audit. An audit rule was identified and error coding was implemented, a process easy to replicate for future research. The error classification method for coding data is consistent with other studies [1,18,19]. Examining the heterogeneity of error coding and what the literature classifies as an error differs. A definition to determine data quality and error within published literature is warranted.

Our finding that >30% of total error in both audits indicates the importance of a SDV audit for identifying error. The proportion of error trended upward as length of study increased, which is consistent with the Duke Clinical Research Institute [7].

However, completing multiple audits throughout the length of the study and providing CQI can improve data quality and integrity. It is accepted in published literature that if >10% of a dataset is erroneous, the data be considered unreliable [20]. A 5% quality assurance rule was selected within this research setting. This study had five data entry personnel and a relatively small dataset conducted at a single-site, therefore, expectations for quality of data was high. Within audit-1 physiological data was the only section to have an error rate <5%, as data for this section was electronically generated; therefore, not recorded data had no impact on error calculation. Anthropometric and medicines data sections increased in error recording a total error >10% for audit-2. Greater error rate could be due to data obtained through 'participant recall', which is subjective to communication and memory.

In tightly regulated prospective clinical trials most databases have a lower acceptance criteria of 0.5% error [7]. However, in a clinical research setting, the average error rate of a source-to-database audit is roughly 10% [1,19]. Duda et al. [19] reported on having an error >10% ranging from 2% to 34% across seven different audit sites. Similarly, the EROTC study [18] found across 15 centers correct data ranged from 78-98% finding data quality was influenced by training and knowledge of data management and those entering data. In comparison to findings in this study, the percentage of error ranged within different data sections of the audit and an increase in error could be due to five different personnel reporting, recording and entering data. Conflicting with previous research Nahm, Pieper and Cunningham [2] took a holistic approach to assess data quality and found a significant decrease of 4% when verifying source-to-database. Within the literature, there are inconsistent findings regarding "acceptable" error rates. Therefore, a standardised method for SDV audits needs to be recognised.

After reviewing the limited published literature we believe a 5% error rate within electronic datasets should be the "gold standard" for determining data quality within a clinical setting and believe a 10% error rate published within multiple studies is too large to draw on reliable and valid results. Errors vary depending on the type of dataset, and a 10% error rate may be more acceptable for manually transcribed data.

This study's results are limited to the University of Wollongong and IHMRI and development of clinical trial operations. Audit results are subject to variations in procedure and disclaimer of trials design. Audits results presented here are limited to source-to-ESR audits and from the authors' understanding this is the first of it's kind within published literature. Based on our experience with an audit methodology and rule, the use of different error coding and variations in method design for calculating error rates vary widely across the industry. One auditor completed the audit process and results are limited to their knowledge and critique. Knowledge and experience was gained throughout the audit process. Hence, audit-2 may be more likely to uncover errors when compared to audit-1. Only a 10% random sample of participant records was audited and a true error rate may differ from the estimated error rate reported in this paper.

The SDV audit allowed for identification of weaknesses within the data recording, collection and storing process and how these can be resolved before erroneous data can cause problems within results. It is recommended a CQI cycle framework is developed to plan, do, check and act on erroneous data points. Conducting an educational training workshop focusing on the importance of data collection and entry highlights the significance of data quality to data entry personnel, and research team. Standardised procedures are required to structure CRFs to ensure consistent documentation is

produced. Double-checking and revising 100% of data points entered to the ESR before a third SDV audit aims to maximise quality assurance. Future research should focus on implementing a more standardised method of SDV audits.

4. Conclusion

The findings of this study demonstrate that monitoring data quality through the use of a SDV audit can identify data quality and integrity issues within a clinical research setting. The study has developed a simple yet effective method that can be employed to determine error within a dataset. This can be applied not only to clinical research but also to all data quality assurance studies.

References

[1] M. Mealer et al., Remote Source Document Verification in Two National Clinical Trials Networks: A Pilot Study, *PLoS One,* **8** (2013), e81890
[2] M.L. Nahm, C.F. Pieper and M.M. Cunningham, Quantifying Data Quality for Clinical Trials Using Electronic Data Capture, *PLoS One,* **3** (2008), e3049
[3] Y.W. Lee et al., *Journey of Data Quality*, MA:MIT Press, Cambridge 2006
[4] M.N. Zozus et al., Assessing Data Quality for Healthcare Systems Data Used in Clinical Research (version 1.0), *National Institutes of Health (NIH) Health Care Systems research Collaboration*, 2014; Available from: http://sites.duke.edu/rethinkingclinicaltrials/assessing-data-quality/
[5] International Conference on Harmonisation. Harmonisation. Harmonized Triparitite Guideline: Guideline for Good Clinical Practice, 1996; Available from: http:www.ich.org/cache/compo/276-254-1.html
[6] C. Baigent et al., Ensuring trial validity by data quality assurance and diversification of monitoring methods, *Clinical Trials (London England),* **5** (2008), 49-55
[7] R. Rostami, M. Nahm, C.F. Pieper, What can we learn from a decade of database audits? The Duke Clinical Research Institute experience, 1997—2006, *Clinical Trials (London, England),* **6** (2009), 141-150
[8] R.V. Gómez-Rioja et al., Current status of verification practices in clinical biochemistry in Spain, *Clinical Chemistry And Laboratory Medicine: CCLM / FESCC,* 51 (2013), 1739-1746
[9] G.J. Kuperman et al., Developing data content specifications for the Nationwide Health Information Network Trial Implementations, *Journal of the American Medical Informatics Association,* **17** (2010), 6-12
[10] T. Luukkonen et al., The measurement of international scientific collaboration, *Scientometrics,* **28** (1993), 15-36
[11] S.N. Duda, F.H. Wehbe and C.S. Gadd, Desiderata for a Computer-Assisted Audit Tool for Clinical Data Source Verification Audits, *Studies in health technology and informatics,* **160** (2010), 894
[12] C.S. Wagner and L. Leydesdorff, Mapping the network of global science: comparing international co-authorships from 1990 to 2000, *Internation Journal of Technology and Globalisation,* **1** (2005), 185-208
[13] M. McKee, Routine data: a resource for clinical audit? *Quality Health Care,* **2** (1993), 104-111
[14] Centre for Clinical Governance Research in Health (CCGR), *Clinical audit: a comprehensive review of the literature,* Faculty of Medicine, University of New South Wales, Sydney Australia, 2009; Available from: http://www.health.vic.gov.au/clinicalengagement/downloads/pasp/literature_review_clinical_audit.pdf
[15] N. Dixon and M. Pearce, Guide to Ensuring Data Quality in Clinical Trials, Healthcare Quality Improvement Partnership, 2010; Available form: http://www.hqip.org.uk/assets/LQIT-uploads/Guide-to-ensuring-data-quality-in-clinical-audits-8-Sep-10.pdf
[16] R.C. Macefield, A.D. Beswick, J.M. Blazeby and J.A. Lane, A systematic review of on-site monitoring methods for health-care randomised controlled trials, *Clinical Trials (London, England)*, **10** (2013), 104-124.

[17] World Health Organisation (WHO) Regional Office for the Western Pacifica, Improving Data Quality A guide for developing countries, 2003; Available at: http://www.wpro.who.int/publications/docs/Improving_Data_Quality.pdf
[18] K. Vantongelen, N. Rotmensz and E. Van Der Schueren, Quality Control of Validity of Data Collected in Clinical Trials, *European Journal of Cancer and Clinical Oncology,* **25** (1989), 1241-1247
[19] S. N. Duda et al., Measuring the Quality of Observational Study Data in an International HIV research Network, *PLoS One,* **7** (2012), e33908
[20] D.R. Clarke, Verification of data in congenital cardiac surgery, *Cardiology in the Young,* **18** (2008), 177-187

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-114

The Hare and the Hortoise: The Potential Versus the Reality of eTP Implementation

Kyaw Kyaw HTAT [a], Patricia A H WILLIAMS [a,c] and Vincent McCAULEY [b,c]
[a] *School of Computer and Security Science, Edith Cowan University*
[b] *Integrating the Healthcare Enterprise (IHE) Australia*
[c] *Health Level 7 (HL7) Australia*

Abstract. In a health system increasingly driven by cost constraints, there is a focus on improved electronic transfer of information to support healthcare delivery. One area of healthcare that has moved more quickly than others to achieve this is prescribing in the primary care environment. Whilst the move to electronic transfer of prescriptions has reduced transcription errors, the regulatory environment persists with handwritten signatures. This constraint, whilst addressed slowly with technology solutions, needs support from legislative change. The ultimate step is to have a secure mobile model, which would support the move to a fully-electronic, paperless transaction model.

Keywords. eTP, electronic Transfer of Prescription, implementing eTP, HL7

Introduction

The National Health and Hospital Reform Commission (NHHRC) recognises that e-health plays a vital role in realising Australia's health reform recommendations [1], and is the key to improving Australian healthcare system whilst supporting a maintainable system [2]. Electronic Transfer of Prescriptions (eTP) is an important contributor in an e-health-enabled healthcare system that ensures medicines information is accurately and securely shared, providing a range of healthcare benefits for both prescribers and consumers [3, 4]. In an environment where 209.8 million prescriptions were filled in the 2013-2014 financial year, an increase of 6.3% on 2012-2013, streamlining the prescription process is vital [5]. This is achieved through sharing of precise patient medication information between prescriber and dispenser [3]. The eTP process allows for electronic generation of a prescription by a prescriber and electronic signature authentication, which is then transmitted securely to a pharmacy.

As the demand for mobile applications to support healthcare provision grows, there is a need to explore opportunities and seek solutions to the issues of secure transmission and use of data for health in a mobile environment. This paper uses eTP as an example of the pathway of technological development from the paper based manual prescription process to a fully mobile, paperless paradigm. It reviews the existing methods of transfer of prescription information including current practice, software capabilities, and regulation and legislative constraints at the Commonwealth, State, and Territory levels. Instead of simply providing a comparative review of various implementations, it presents a snapshot of the current situation in order to provide a context and further it proposes a new mobile fully-electronic solution.

1. Methods for Transfer of Prescriptions

As both hardware and software technology have evolved, there has been a progression in information transfer from a manual prescribing process to a hybrid manual/electronic solution. Figure 1 demonstrates the conventional manual prescribing model with the prescriber writing on a pre-printed prescription pad. Once signed, the prescription is given to the patient, who then presents it to the pharmacy where the prescription details are transcribed into an electronic pharmacy dispensing system for dispensing. This information is also used for Pharmaceutical Benefits Scheme (PBS) claiming and repeat dispensing. This process may include verification of the prescription details with the prescriber, and it is vulnerable to loss of the prescription by the patient, as well as transcription errors in the pharmacy data-entry process.

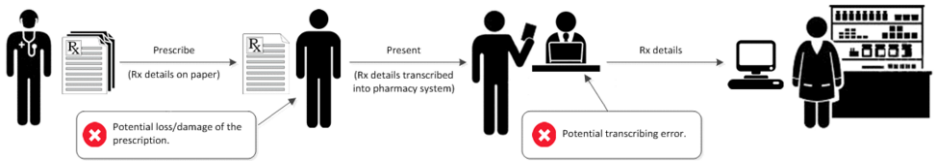

Figure 1. Manual prescribing process.

The introduction of the Practice Incentive Program (PIP) by the Australian Government for desktop computing in general practice in the late 1990's, saw the transition to printed prescriptions and subsequently electronic process inclusion as part of the prescribing workflow [6].

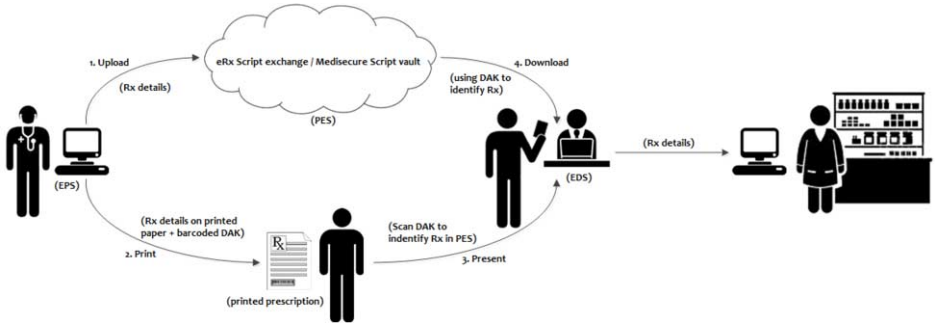

Figure 2. Current electronic prescription transfer process.

Figure 2 describes the prescribing model currently used by 95.7% of GPs in Australia [7]. This model implements eTP technical specification. eTP version 1.1 uses the Prescription Exchange Service (PES), Electronic Prescribing System (EPS) and Electronic Dispensing System (EDS) as key elements:

- The Prescription Exchange Service (PES) is an intermediary service, which enables secure transmission of electronic prescription information between prescribers and dispensers [8].
- The Electronic Prescribing System (EPS) is a component of the prescriber's clinical software package for generating an electronic prescription, digitally signing it and uploading it to the PES [8].
- The Electronic Dispensing System (EDS) is a pharmacy software component, which downloads the electronic prescription from the PES and submits dispense-records to the PES upon dispensing [8].

In this model, GPs use clinical software that has an EPS component for generating prescriptions and upload to one of two script exchanges (PES). Each electronically generated prescription is identified by a unique Document Access Key (DAK), which is provided to the patient encoded as a barcode on the printed and signed Prescription Notification slip. The slip contains information identical to the prescription. When the slip is presented to the pharmacy, the prescription detail is downloaded by the pharmacy's eTP enabled EDS from the PES, using the DAK, as shown in Figure 2. This eliminates the need for verification of the prescription details, and transcription errors. The downloaded prescription is used to dispense the medication and for secondary uses such as PBS claiming. The EDS then provides a record of the dispensed medication to the PES. Whilst existing, the automatic dispense notification service to the originating prescriber is currently disabled at the request of the Royal Australian College of General Practitioners, due to potential implications for clinician duty of care [12].

A mobile application from one PES supplier was released in 2014 to enhance this process model (Figure 2) by allowing patients to scan the DAK barcode from the prescription to their mobile phone, and submit it to their choice of pharmacy, securely for a scheduled pickup. This model still uses the printed Prescription Notification with prescription details as a transfer medium for passing the DAK between the prescriber and dispenser. The prescriber's signature on the printed prescription is mandated by relevant Acts/Regulations (e.g. Poison Regulation 1965 Regulation 51.(1B) in Western Australia). This requirement will be replaced once the use of digitally signed electronic prescriptions has legislative approval.

2. Adoption Potential and Related Issues

Figure 3 depicts the levels of eTP adoption, the extent to which eTP is implemented, and its influence on the information workflow and the form in which the information is communicated. The level of adoption of eTP varies across the different sectors of the healthcare industry, despite being a key government initiative to improve the delivery and quality of healthcare.

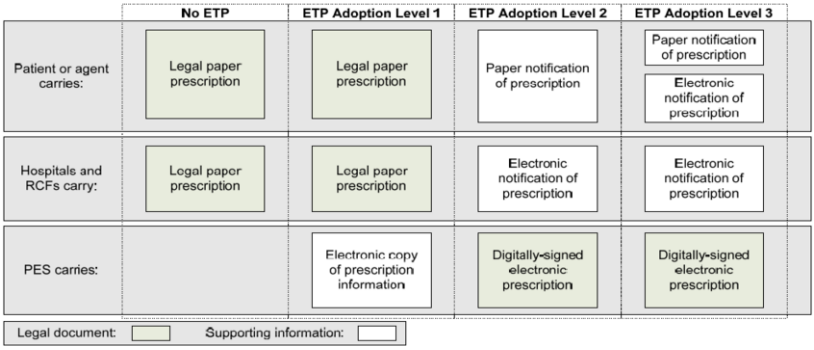

Figure 3. Level of eTP adoption [9].

In Level 1 the printed prescription is both the legal prescription for dispensing and the transfer medium for delivering the DAK identifier to the dispenser. Having the prescription details printed with the DAK benefits the patient, as the printed prescription details may be used for dispensing if the pharmacy's EDS is not eTP enabled or access to PES is not available. However, this requires the printed prescription to have the prescriber's handwritten signature on it as mandated by the s. 51(1B) of the Poisons Regulations 1965 in WA and similar legislation in other States. However, using a data storage device as the transfer media for the electronic prescription, instead of the printed paper version, means the written signature of the prescriber is no longer required as it is exempted by the s. 51 (1A) and s. 51(1C) of the Poisons Regulations 1965, and s. 9(1) and s. 9(3) of the Electronic Transaction Acts 1999.

Level 2 adoption uses the printed prescription notification as a transfer medium for delivering the identifying DAK to the dispenser. The printed prescription notification also contains the same prescription details as the electronic prescription thus facilitating dispensing if access to PES is not available. However, the same principles and restrictions apply as in Level 1 with regard to the prescriber's handwritten signature. In the current electronic prescription transfer process, the pharmacy's eTP enabled EDS downloads the prescription details from the PES using the DAK, upon receiving the printed prescription or the prescription notification submitted by the patient/agent.

Level 3 allows for the same conditions as Level 2 but replaces the paper notification with a fully-electronic notification.

3. Designing Solutions to Meet Compliance

Whilst the Australian Government has removed Commonwealth legislative barriers to electronic prescribing, by implementing changes to the National Health (Pharmaceutical Benefits) Amendment Regulations 2006, the State and Territory legislative barriers remain. Alignment with Commonwealth amendments is occurring slowly, and this will provide rules for electronic prescribing and dispensing in the respective jurisdictions. Table 1 lists the Commonwealth, as well as State and Territory Acts and Regulations that have been repealed and/or amended to accommodate implementation of eTP.

Table 1. Commonwealth, State and Territory Acts enabling the implementation of eTP.

Jurisdiction	Acts/Regulation
Commonwealth	Electronic Transactions Act 1999
Commonwealth	National Health Act 1953; National Health (Pharmaceutical Benefits) Regulations 1960
NSW	Poisons and Therapeutic Goods Regulation 2008
VIC	Drugs, Poisons and Controlled Substances Regulations 2006
QLD	Health (Drugs and Poisons) Regulation 1996
WA	Poisons Act 1964; Poisons Regulations 1965
SA	Controlled substances Act 1984; Controlled substances (Poisons) Regulations 2011
TAS	Poisons Act 1971; Poisons Regulations 2008
ACT	Medicines, Poisons and Therapeutic Goods Act 2008; Medicines, Poisons and Therapeutic Goods Regulations 2008
NT	Medicines, Poisons and Therapeutic Goods Act 2012

Other standards, specifications, and principles that support and govern the implementation of eTP in Australia include: Electronic Transactions Act 1999 (Commonwealth) and Electronic Transactions Act 2011 (WA), Australian Privacy Principles 2014, ATS 4888.1–7 (2013) Electronic transfer of prescriptions using Health Level 7 (HL7) Clinical Document Architecture (CDA), and AS 4700.3-2014 - Electronic messages for exchange of information on medicines prescription using HL7 V2.5. Whilst not exhaustive, this highlight the complexity of designing solutions. In other words, these Acts, regulations, and standards influence the legislative requirements and specifications that must be met in design and development of eTP.

4. A New, Fully Mobile Solution

Whilst the *Electronic Transactions Act 1999* primarily supports the creation, transfer and storage of the electronic prescription, amendments 51(1A) and 51(1C) of the *Poisons Regulations 1965* effectively allows an electronic prescription to be a legal document without the prescriber's written signature. Combined with other changes in governance the Commonwealth and States have made to enable e-health, these two amendments are sufficient to support an ETP Level 3 model.

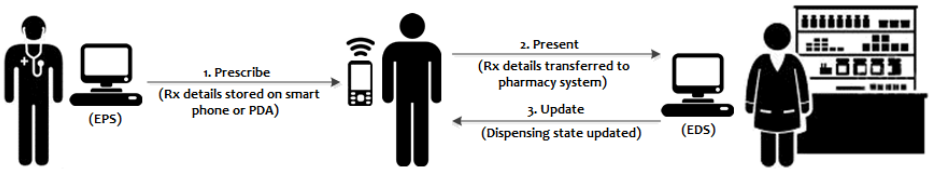

Figure 4. Proposed fully-electronic mobile prescription transfer process.

A fully-electronic mobile prescription transfer model is proposed (Figure 4). The EPS generates an electronic prescription, encrypts it using the DAK as per the data

security conformance guidelines in ATS4888.2, signs the DAK with the prescriber's Medicare digital certificate, and then transfers it to the patient's mobile device. The use of digital certificates not only provides a way to authenticate the prescriber but also assures the confidentiality and integrity of the information transferred. The encrypted electronic prescription is stored on the mobile device in the same way it is stored within the PES in the current prescribing model. When presented at the pharmacy, the encrypted prescription and DAK are transferred to the pharmacy system, the prescriber's digital certificate is verified, and then the prescription is decrypted using the DAK. This model bypasses the PES entirely by using the mobile device as the transfer medium for the electronic prescription. Once dispensed, the pharmacy's EDS uploads the dispensing information into the NPDR. In this model, the prescription is issued and transferred in fully-electronic form, thus removing the requirement for the prescriber's written signature in accordance with section 51(1A) of the Poisons Regulations 1965.

This proposed eTP transfer model supports eTP adoption stages Levels 1 to 3 as long as there is a mechanism to transfer the electronic prescription from the prescriber's EPS to the mobile storage device and from the mobile storage device to the dispenser's EDS securely. This model is envisaged to use Near Field Communication (NFC) technology as the preferred transfer mechanism. NFC is designed for use in close proximity (i.e. up to a few centimetres) for secure data transfer and supports strong security features that facilitate highly secure transfer and storage of data. The NFC technology's reliability and practicality is evident by its use in the banking industry (e.g. Commonwealth Bank for its product, Tap & Pay). Nevertheless, this preference of employing NFC for data transfer is not based solely on the technical viability but also on the consumer acceptance and confidence in the technology. NFC's simplicity from a user perspective, enables easy information sharing NFC is now available on all recent model mobile phones. In the current hybrid transfer model, the PES makes uploaded prescriptions available to dispensers as well as preventing access to those that have been cancelled, are expired or fully dispensed. For that purpose, PES updates the dispensing state of each prescription after each dispense. In the proposed model, the smart phone utilised as the mobile storage device makes the prescription available to the dispensers and the dispensing state of the prescription is updated by the dispenser's EDS directly to the mobile storage device. Due to the connectionless nature of the proposed model, cancelling the prescription by the prescriber requires additional services such as SMS to update remotely the dispensing state of the prescriptions stored on the mobile device

5. Conclusion

The Commonwealth, States, and Territories have repealed and/or amended Acts and Regulations, and developed and adopted many standards and specifications in order to pave the way for implementing eTP. The legislative approval for the legal use of digitally signed electronic prescription is one of the last steps supporting the efficient use of electronic information communication in electronic prescribing. The proposed model can be implemented within the existing legislative framework, reduces complexity, and removes the need for ongoing major supporting infrastructure with its associated cost. In addition, users will be empowered and reassured that their sensitive medication data is not available to third parties. The model is very efficient and does not

require internet connectivity for basic functionality. Therefore, it provides an effective solution in all areas including remote locations with poor or no connectivity.

References

[1] Australian Government. (2009). A Healthier Future for All Australians – Final Report June 2009. Retrieved March, 2015 from: http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/1AFDEAF1FB76A1D8CA257600000B5BE2/$File/Final_Report_of_the%20nhhrc_June_2009.pdf
[2] Bennett, C.B. (2013). Are we there yet? A journey of health reform in Australia. M JA 2013; 199 (4): 251-255.
[3] AMA Position Statement. [2009] Retrieved March, 2015, from Australian Medical Association: https://ama.com.au/sites/default/files/documents/Microsoft_Word_Position_Statement_on_Electronic_Prescription_Transfer_Sys%E2%80%A6_0.pdf
[4] NPS MedicineWise. (2012). Ehealth. Retrieved from http://www.nps.org.au/topics/e-health
[5] Expenditure and prescriptions twelve months to 30 June 2014 [2015]. Retrieved March, 2015 from PBS: http://www.pbs.gov.au/statistics/2013-2014-files/expenditure-and-prescriptions-12-months-to-30-june-2014.pdf
[6] Quinlan, F. (2000). Electronic prescribing in general practice: one small step. Australian Prescriber,(23):50-1.
[7] Henderson, J., Pollack, A., Gordon, J., & Miller, G. (2014). Technology in practice – GP computer use by age. Australian Family Physician, 43 (12),831-831
[8] ePrescriptions. [2012] Retrieved March, 2015, from NEHTA: http://www.nehta.gov.au/component/docman/doc_download/1658-eprescriptions-factsheet?Itemid=
[9] Gregory, T. (2013). Electronic prescribing to reduce medication error. Retrieved March 2015 from RACGP Conference 2013: http://gpconference.com.au/gp13/presentations/
[10] McDonald K. (2013, March 12). RACGP prefers opt-in model for dispense notifications. *PULSE+IT*

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-121

Use of Smartphones to Estimate Carbohydrates in Foods for Diabetes Management

Jurong HUANG [a], Hang DING [a,1], Simon MCBRIDE [a], David IRELAND [a], Mohan KARUNANITHI [a]
[a] *The Australian e-Health Research Centre, CSIRO, Royal Brisbane and Women's Hospital, Brisbane, Australia*

Abstract. Over 380 million adults worldwide are currently living with diabetes and the number has been projected to reach 590 million by 2035. Uncontrolled diabetes often lead to complications, disability, and early death. In the management of diabetes, dietary intervention to control carbohydrate intake is essential to help manage daily blood glucose level within a recommended range. The intervention traditionally relies on a self-report to estimate carbohydrate intake through a paper based diary. The traditional approach is known to be inaccurate, inconvenient, and resource intensive. Additionally, patients often require a long term of learning or training to achieve a certain level of accuracy and reliability. To address these issues, we propose a design of a smartphone application that automatically estimates carbohydrate intake from food images. The application uses imaging processing techniques to classify food type, estimate food volume, and accordingly calculate the amount of carbohydrates. To examine the proof of concept, a small fruit database was created to train a classification algorithm implemented in the application. Consequently, a set of fruit photos (n=6) from a real smartphone were applied to evaluate the accuracy of the carbohydrate estimation. This study demonstrates the potential to use smartphones to improve dietary intervention, although further studies are needed to improve the accuracy, and extend the capability of the smartphone application to analyse broader food contents.

Keywords. Dietary assessment, carbohydrates, diabetes, mobile application

Introduction

Diabetes has become a leading global chronic disease, and imposes a huge burden to healthcare systems in the world. Currently, over 380 million adults worldwide are living with diabetes and the number is projected to reach 590 million by 2035 [1]. If uncontrolled, diabetes will progressively damage nervous and circulation systems, and lead to numerous complications disability, and early death. In 2013, 1.5 million deaths were directly caused by diabetes in the world [2]. In 2010, the global health expenditure on diabetes was estimated to be over US$376 billion [3].

[1] Corresponding Author: Hang Ding, The Australian e-Health Research Centre, CSIRO, Level 5 – UQ Health Sciences Building 901/16, Royal Brisbane and Women's Hospital, Herston 4029, Brisbane, Australia. Email: hang.ding@csiro.au.

Interventions to control dietary carbohydrate intake are considered essential in the management of diabetes. These interventions are based on the theory that carbohydrate is the predominant macro-nutrition contributing to the rise of blood glucose level regulated in the carbohydrate metabolism [4]. Accordingly, clinical interventions on excessive intakes of carbohydrate are beneficial to alleviate the burden to the metabolism. For patients with the insulin therapy, carbohydrate intervention is also needed to help optimise insulin dosages as inappropriate dosages are often detrimental or even life-threatening. Numerous studies have demonstrated that interventions on dietary carbohydrate improve the management of both type I and II diabetes [5,6]. A recent review study by Feinman analysed the carbohydrate intervention from different aspects including efficacy, risks, and potential benefits. It proposed to use carbohydrate intervention as the first approach in the diabetes management [7].

Traditionally, the intervention of dietary carbohydrate mainly relies on a paper based diary. To estimate carbohydrates, patients need to manually look up food nutrition tables to get carbohydrate concentrations, weigh foods, calculate the amount of carbohydrate, and write down the amount in a diary for reviewing. Importantly, diabetic patients need to frequently repeat the estimation task for each food object, and gather the carbohydrate information on a daily basis. Therefore, the traditional approach for many patients is inconvenient and even burdensome. Additionally, some specific knowledge and skills are normally required to achieve a certain level of accuracy and reliability. A recent study showed that inaccurate carbohydrate estimations were common in clinical studies, and were associated with uncontrolled blood glucose variability [8].

The recent advent of smartphone and Internet applications provides numerous opportunities to address patients' healthcare needs in their daily lives. This study proposes a proof-of-concept using smartphone image processing technologies to conveniently estimate carbohydrates. To do this, we developed a smartphone application integrated with three major components: image classification of food photos, volume estimation, and carbohydrate calculation. A small fruit database was generated to train and test the classification performance. Six fruits photos from a real smartphone were analysed as well. Finally, the results were discussed. The objective of this study is to explore the feasibility to use smartphones to estimate dietary carbohydrate intakes for the management of diabetes.

1. Methodology

An application was developed on the Android operating system. This application used an open-source computer vision library, called OpenCV [9], to classify photos of foods, and finally estimated the corresponding carbohydrates. The flowchart of the data analysis process is demonstrated in Figure 1. With this application, a patient uses a smartphone to take a photo of some food. The photo is then automatically analysed through three major steps: food classification, volume estimation, and carbohydrate calculation. The first two steps respectively determine the food type and volume (V). According to the food type, the application searches a fruit database to obtain the density of the food (ρ) and carbohydrate concentration (c). Finally, the amount of carbohydrates contained in the food is calculated, and reported to the patient.

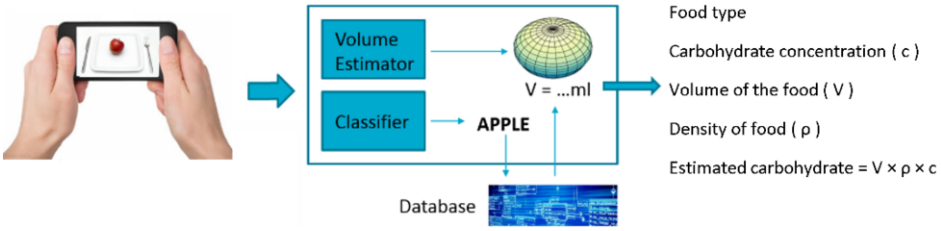

Figure 1. The flowchart of the data analysis in the proposed smartphone application.

In the food classification, a widely used classifier called Support Vector Machine (SVM) is implemented [10]. SVM is a supervised learning model with a linear classifier. A training dataset can be denoted as $\{ x_i, y_i \}$, where i=1… , n; x_i is a feature vector; y_i is a class label normally denoted as $y_i \in \{ -1 , 1 \}$. Given the dataset, the SVM classifier solves the constrained minimisation according to the equation given below:

$$\min_{w,\, b_0} L(w,\, b_0) = \frac{1}{2}\|w\|^2 \;\; satisfying \; y_i(w^T x + b_0) \geq 1 \forall i$$

where w is a weight vector, and b_0 is a constant. Through a supervised training process, optimal b_0 and w are obtained.

The selection of features (x_i) for the SVM classifier is essential because it determines the classification performance [11]. Normally, x_i contains different subgroups of visual features in an image, called descriptors. This study applied three descriptors: scale invariant features, colour features, and texture features. The representations for each descriptor are shown in Figure 2. The scale invariant features were obtained from an algorithm, called Scale Invariant Feature Transform (SIFT). SIFT has been popularly applied in computer vision studies because it can quantify features independent of their scales and orientations in the image. In this study, the output data of SIFT were further categorised by a method called Bag-of-Words (BOW) [12]. The colour features were directly obtained from the primary RGB colours (red, green, or blue). The descriptor for texture was quantified by the Local Binary Pattern (LBP) method to reflect the changes in local areas of a food image. In the LBP method, an image was segmented into small squares, 16x16 pixels in each square. Then each square was compared with its neighbours in eight different directions such as top and top-left. Finally, the occurrences of the features from BOW, RGB, and LBP were represented by a histogram, and finally provided to the SVM classifier.

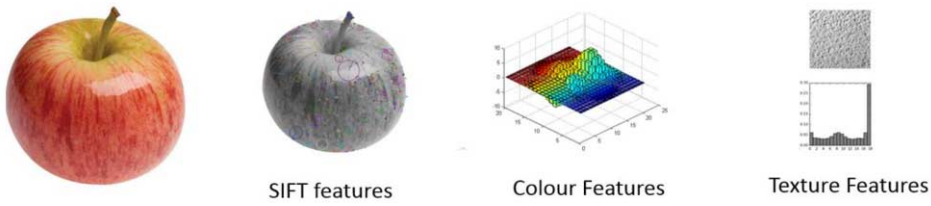

Figure 2. The three feature descriptors used the SVM classification.

The volume of food was estimated using a modelling approach. Figure 3 shows the approach using a ball-shaped model to estimate the volume of an apple. A standard credit card was placed by the apple to provide a spatial scale reference. According to the reference, a distance measured from the image coordinate system was converted to the distance in the real space. The application used a light-intensity threshold to segment the apple from the background, and consequently obtained the contour of the apple and its central axis of symmetry. By revolving the contour around the central axis, a ball-shaped model was constructed, and its volume was determined.

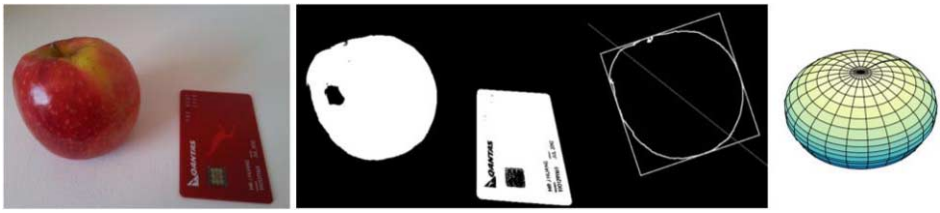

Figure 3. The ball-shaped model used to estimate the volume of an apple.

To train the SVM classifier, a fruit databased was collected. This database consisted of 10 types of fruits including orange, apple, pear, tomato, strawberry, banana, mango, avocado, pineapple, and kiwi fruit. Each fruit type contained 60 images. The database was randomly separated into a training dataset (50 images each fruit type), and a testing dataset (10 images each fruit type). This study used the accuracy to represent the performance of the SVM classifier. The accuracy (A) is defined as: $A = (TP + TN) / (TP + TN + FP + FN)$, where TP is true positive, TN is true negative, FP is false positive, and FN is false negative.

To evaluate the performance of the volume estimation, another image dataset was obtained from a smartphone (Samsung Galaxy S2). The database consisted of six photos of three different fruits: three apples, one peach, and two tomatoes. The images in the dataset are shown in Figure 4. The water displacement method was used to measure the actual volume of the six fruits. The estimated volume was then compared with the measured volume. Finally, the error rate was calculated for the evaluation.

Figure 4. Six fruit images collected to assess the performance of the volume estimation algorithm.

2. Results

The performance of the SVM classifier using the three descriptors and their combination is shown in Figure 5. The figure shows that the accuracy of the individual descriptors varied due to different fruits and the classification with the combined descriptors was improved noticeably. In the latter case, the classification of avocados, pineapples, and kiwifruits achieved 100% accuracy. The poorest performance was in

classifying tomatoes, 70% accuracy. The overall accuracy of the SVM based classification was 90%.

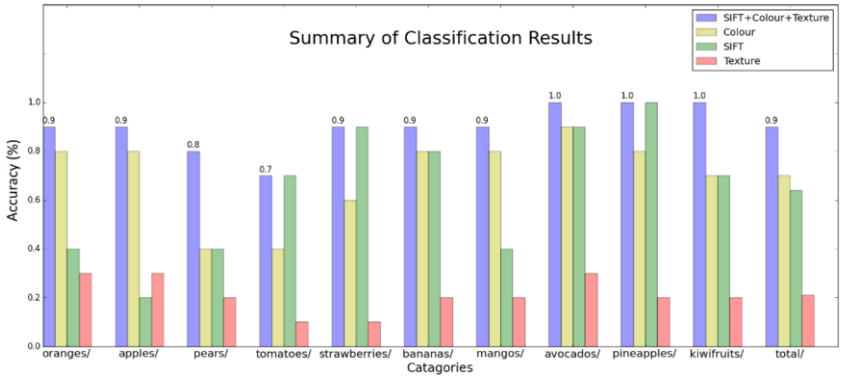

Figure 5. Classification result on the 10 selected fruits.

The result of the volume estimation and carbohydrate calculation is shown in Table 1. The highest error rate in the volume estimation was 13.9%; the lowest was 4.3%; and the average was 6.86%. In the estimation of carbohydrate, the highest and lowest error rates were 16.1% and 2.45% respectively; and the average was 8.18%.

Table 1. Summary of the volume and carbohydrate estimations, compared with the actual values measured from the water displacement and weight scale.

Test Item	Model Volume (ml)	Actual Volume (ml)	Error Rate (%)	Estimated Carbs (g)	Actual Carbs (g)	Error Rate (%)
Peach	158	151	4.43	16.3	15.9	2.45
Apple1	165	173	4.85	18.5	21.3	15.1
Apple2	172	190	13.9	19.3	22.4	16.1
Apple3	201	198	1.49	22.5	23.7	3.56
Tomato1	21	22	4.76	0.74	0.78	5.41
Tomato2	17	19	11.7	0.62	0.66	6.45
	Average Error		6.86			8.18

3. Discussion

The use of smartphones for analysing foods remains new in the literature. This study focusing on the analysis of fruits demonstrated that the three descriptors (SIFT, colour,

and texture) contributed differently to the classification, and their combined performance was noticeably superior to that of single descriptors. The results indicate that the combination of different descriptors was effective in this study. This study achieved a mean error rate of 6.86% in the volume estimation. The performance is consistent with the result from another study using a Disparity and Depth Map (DDM) based reconstruction approach [13], which reported an error rate of 7.7%. Another study also used a similar technique, and achieved a mean error of 10% [14]. In comparison, our approach is limited in the analysis of irregular objects, as fitting an irregular object to a model is often difficult. The DDM approach would be less sensitive to the shape irregularity, but require more computational power and accurate camera calibrations.

The use of smartphones for carbohydrate interventions would be beneficial in the management of diabetes. Compared with the traditional paper based approach, this approach does not require specific knowledge or skills to estimate carbohydrates in foods. The estimation through a smartphone application would be much faster. A smartphone is also easier to carry and fit in with a user' lifestyle. Additionally, the digitised data including food photos and carbohydrates can be timely shared via Internet for interventions. Such data sharing will enable dieticians, nutritionists, and other healthcare professionals to simultaneously involve in the patient care.

The proposed approach is only a conceptual framework, and has many limitations. Although the study demonstrated an error rate of 8.6% in estimating carbohydrates, the result does not reflect its real performance in practical applications, as the datasets used here are very limited. Importantly, this study only focused on analysing limited set of fruit images, while practical applications would require to analysis a wide range of foods with complex shapes.

Due to these limitations future studies are required to improve and extend the smartphone application. The application needs to be evaluated using a large food-image database. Since errors in the classification are inevitable, self-learning mechanisms should also be considered to automatically and continuously updating the database in the application. To extend the application for the analysis of various foods, multiple levels of image classifications would be needed. Additionally, features and classifiers at different levels must be optimised. The nutrition databases also require to be extended for estimating carbohydrates in a larger range of foods. In the future, we also need to engage a consumer group consisting of people with diabetes and associated clinicians on further improving and evaluating usability of the system.

4. Summary

Intervention for dietary carbohydrate intake is essential in the management of diabetes. This study proposed a proof of concept using smartphones to estimate carbohydrates in foods. The results from the experiment showed a certain level of accuracy in the analysis of fruits. This study demonstrates a great potential to use smartphones to help estimate carbohydrates and improve the management of diabetes, although much future work is needed to improve its reliability and accuracy, and extend its ability in the analysis of a large range of foods with complex forms.

References

[1] L. Guariguata. Global estimates of diabetes prevalence for 2013 and projections for 2035. Diabetes Research and Clinical Practice, vol. 103, no. 2, pp. 137-149, Feb, 2014.
[2] World Health Organization. Global Health Estimates: Deaths by Cause, Age, Sex and Country, 2000-2012. Geneva, WHO, 2014.
[3] P. Zhang. Global healthcare expenditure on diabetes for 2010 and 2030. Diabetes Research and Clinical Practice, vol. 87, no. 3, pp. 293-301, Mar, 2010.
[4] Slama G. Correlation between the nature and amount of carbohydrate in meal intake and insulin delivery by the artificial pancreas in 24 insulin-dependent diabetics. Diabetes 1981; 30: 101–05.
[5] K. J. Bell. Efficacy of carbohydrate counting in type 1 diabetes: a systematic review and meta-analysis. Lancet Diabetes & Endocrinology, vol. 2, no. 2, pp. 133-140, Feb, 2014.
[6] A. Elhayany. A low carbohydrate Mediterranean diet improves cardiovascular risk factors and diabetes control among overweight patients with type 2 diabetes mellitus: a 1-year prospective randomized intervention study. Diabetes Obesity & Metabolism, vol. 12, no. 3, pp. 204-209, Mar, 2010.
[7] R.D. Feinman. Dietary carbohydrate restriction as the first approach in diabetes management: Critical review and evidence base. Nutrition, Volume 31, Issue 1, Pages 1–13, January 2015.
[8] A.S.Brazeau. Carbohydrate counting accuracy and blood glucose variability in adults with type 1 diabetes. Diabetes Res Clin Pract; 99(1):19-23. Jan 2013.
[9] http://opencv.org/
[10] DT.Nguyen. Food image classification using local appearance and global structural information, Neurocomputing, 140 242–251. 2014.
[11] O. Chapelle. Support Vector Machines for histogram-based image classification, IEEE, Transactions on Neural Networks, 10(5):1055–1064. 1999.
[12] G. Lebanon. The Locally Weighted Bag of Words Framework for Document Representation. Journal of Machine Learning Research 8, 2405-2441, 2007.
[13] M.H. Rahman et al., Food Volume Estimation in a Mobile Phone Based Dietary Assessment System, IEEE Signal Image Technology and Internet based Systems (2012), 988–995.
[14] M Anthimopoulos, J Dehais, S Shevchik, BH Ransford, D Duke, P Diem, S Mougiakakou. Computer vision-based carbohydrate estimation for type 1 patients with diabetes using smartphones. Journal of diabetes science and technology. Volume:9 Issue:3 Pages:507-15.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-128

Chat-Bots for People with Parkinson's Disease: Science Fiction or Reality?

David IRELAND [a,1], Jacki LIDDLE [b], Simon MCBRIDE [a], Hang DING [a] and Christina KNUEPFFER [a]

[a] *The Australian E-Health Research Centre, CSIRO, Herston Brisbane*
[b] *Asia Pacific Center of Neuromodulation, University of Queensland, Herston Brisbane*

Abstract. People with Parkinson's disease are known to have difficulties in language and communication. This paper proposes the use of an artificial conversational agent, commonly known as a chat-bot that runs on a smart-phone device and performs two-way conversation with the user. In this paper, initial work on a Parkinson's disease themed chat-bot that interacts with the user relative to their symptoms is presented. Potential dialogues are provided to illustrate the various roles chat-bots can play in the management of Parkinson's disease. The chat-bot can be used for measuring voice and communication outcomes during the daily life of the user, and for gaining information about challenges encountered. Moreover, it is anticipated that it may also have an educational and support role. The chat-bot is now ready for usability testing with a clinical population.

Keywords. Parkinson's disease, artificial intelligence, natural language processing, speech, voice, remote monitoring.

Introduction

While Parkinson's disease (PD) is often recognized by the cardinal symptoms of tremor, slowed movement and rigidity, there are a multitude of motor and non-motor symptoms. Voice changes are experienced by 80-90% of people with Parksinon's disease (PWP) [1] and subsequently changes to their thinking, use of language and mood [2]. Early research focused largely on the various phonation impairments, phoneme articulation and acoustic timing for PWP [3,4]. More recent efforts however have been placed on examining the consequences of difficulties with communication. Studies have shown PWP have problems with conversation initiation, turn-taking, topic management, word-retrieval, and memory [5]. A notable article by Miller *et al.* in [1] examined the impact of changes in communication for PWP by conducting in-depth interviews and found emergent themes of frustration due to losing track mid-sentence and indignity and social withdrawal from being excluded from the conversation.

While there are many standardized voice, language and cognitive formal assessments, the fluctuating nature of PD means that it is important to monitor performance outside of the clinical environment. With the advent of ubiquitous smart-phone technology, autonomous remote monitoring applications that log and analyse multi-domain data

[1] Corresponding Author: David Ireland; E-mail: d.ireland@csiro.au

such as accelerometery, voice and community movement are being increasingly reported [6]. None however, has yet considered the monitoring and logging of conversation. This is perhaps due to the complex ethical and privacy issues surrounding autonomous audio recording. In this paper, we consider the possibility of human-machine converse rather than human-human. Although this could not be considered naturalistic conversation dialogue, we assert that it alleviates privacy issues and is suitable for people who may not have a conversational partner, while still assessing the applied use of communication rather than short, clinical assessments.

Artificial intelligent conversation agents or chat-bots are natural language processing systems that have largely remained in the science-fiction domain due to the enormous challenge of programming systems that mimc human communication. Surprisingly the first chat-bot was developed in 1966 by Weizenbaum and named *Eliza* which famously simulated a Rogerian psychotherapist [7]. Eliza was able to generate responses with surprising intelligibility by simple parsing of the input text and substitution of key words into pre-stored phrases. Despite its obvious limitations, Weizenbaum reported that it was highly anthropomorphized with some users spending hours conversing and refusing to share conversation records [7]. Chat-bots have been reported in the literature for health related applications. Examples include health behaviour change for obesity and diabetes [8]; disease self-management [9]; and health education for adolescents on topics related to sex, drugs and alcohol [10].

This article will describe the realisation of a Parkinson's themed chat-bot and provide potential dialogues. The chat-bot will be used for measuring voice and communication outcomes of people with PD during their daily life, and for gaining information about challenges encountered during community living. It is further anticipated that it may also have an educational and support role.

1. Chat-Bot Framework

Early reported chat-bots solely relied on typed text as the input stimuli, however with modern smart-phone technology, this need no longer be the case. Android and iPhone based smart-phones have both speech-to-text and text-to-speech tools capable of converting spoken acoustic signals into digital text and converting digital text into a digital-synthetic, acoustic voice. How to process the text input and construct a meaningful response has been the main research question of chat-bot researchers for some time now. The most prominent technique for the last decade has been via case-based reasoning and textual pattern matching algorithms in particular the use of a standardised computer language referred to as artificial intelligence mark-up language (AIML).

AIML was developed in early 2000 by Wallace and a worldwide free software community referred to as *bot-masters* [11]. AIML is based on the common eXtensible markup language (XML) which utilises tags to identify commands and specific input stimuli and responses. AIML is based on basic units of dialogue formed from user input patterns and respective chat-bot response. The basic units in AIML are called categories; within categories are a *pattern* and *template*. The pattern tag defines a possible user input while the template tag gives the response. Creation of AIML content requires no advanced computer programming skill and this has likely contributed to the significant amount of content already released by bot-masters. As of 2015, a large collection of

AIML sets have been released under the GNU public license making them freely available. These sets make up approximately 97,431 categories in topics including, politics, religion, science, sex, sports, history, food and geography. A specific example is given below showing when the user speaks "*What is Parkinsons disease*", the chat-bot responds with a "*A neurodegenrative disease*".

```
<category>
  <pattern> What is Parkinson's disease </pattern>
  <template> A neurodegenerative disease </template>
</category>
```

This simplistic example consists of a direct response only; more advanced AIML techniques are often needed to formulate a response that is human-like and non-deterministic. An exhaustive list of AIML features is beyond the scope of this paper, however, the most useful features are:

1. The ability to learn new responses and alter existing responses whilst interacting with a human during run-time.
2. Wild card searches allowing for responses to be generated when an incomplete match of the pattern occurs.
3. A template that includes multiple responses that are randomly chosen during run-time.
4. Scope for internal variables that allow the chat-bot to store information that may be later accessed.
5. A dedicated topic variable that maintains the current topic allowing category to be activated conditioned on the current topic.
6. Internal data-processing, conditional statements and tests that are not visible to the user.
7. Symbolic reduction allowing different patterns to target a single template tag.

2. A Parkinson's Themed Chat-Bot

In designing a chat-bot for PWP, a number of challenges additional to those typically encountered in chat-bot design are anticipated including the motor and non-motor symptoms of PD. It will be important to reduce frustration, commonly experienced during communication, while conversing with the chat-bot. In addition, PWP are likely to have reduced dexterity so any interface will need to consider this in its design.

Despite the efforts made to produce random, human-like conversation, the purpose of the proposed chat-bot is not only to engage the person with Parkinson's disease in general conversation, but also to solicit specific information. Such specifics include information relating to the persons well-being, their current state of symptoms (old and new), what medication was taken and when, and their state of mind. Moreover, the chat-bot has been be programmed to offer exercise encouragement and the handling of depression and suicidal thoughts. The chat-bot can undetake simple common speech assesments by asking for speech samples. Before being deployed, the chat-bot is able to pre-programmed for a list of current symptoms the PWP is experiencing, and what medication they are prescribed. This allows the chat-bot to ask salient questions of the user.

The chat-bot proposed in this work was developed for the Android operating system. Google's speech-to-text engine was used to capture speech and convert to text which is subsequently passed to the chat-bot. The response of the chat-bot was then passed to Google's text-to-speech engine where the chat-bot's response is spoken providing a completely speech operated program. Keyboard functionality for text input was also made accessible if preferred by the user. This helps to address the dexterity and voice concerns that may affect users with PD.

Several AIML sets were developed relevant to the intended data-collection. It should be noted that the chat-bot is programmed to be non-deterministic allowing it to ask the same question in several ways and often changing the topic. Common scneanios include a conversation when Figure 1 the chat-bot is asking about a particular symptom the PWP experiences and whether any new medications are taken (Figure 1). Any new symptoms or medication can be logged and entered into the chat-bots database during it's run-time.

Figure 2 gives the chat-bot asking for a speech sample for a particular common speech assessment with consent sought first (Figure 2). If the PWP agrees, an assessment is randomly chosen from a current list of six protocols. In this instance the chat-bot is asking for a vowel sound where the fundamental frequency and vowel formants are subsequently analysed. In the next clinical assessment the clinician can download speech samples and analyses from the chat-bot's database.

The mood changes associated with PD and increased suicidality which is experienced by some people with PD need to be considered in the design for any chat-bot eliciting information about well-being. Ensuring timely access to appropriate support is important. When a user has expressed depressive symptomatology, the chat-bot is programmed to direct the user to contact a friend or family member (Figure 3). Any phrases indicative of suicide ideation results in a response with to the local help number, following the protocols of [13].

Lastly, the chat-bot is able to learn new responses during its run-time by the user instructing the chat-bot when its answer is not correct (Figure 4). The chat-bot subsequently asks for the correct answer which is permanently stored in its database. Al present, only simple responses can be stored, however this function does allow the chat-bot to be programmed by a non-programmer and for user-centric responses. This is beneficial in health related applications where clinicians could instruct the chat-bot on appropriate responses but may not have the necessary expertise in developing AIML code. Similarly, users could tailor responses to their preferences.

Figure 1. Chat-bot can initiate conversations relevant to the individual's condition and log new symptoms and medications into its database. In this example, exercise is encouraged.

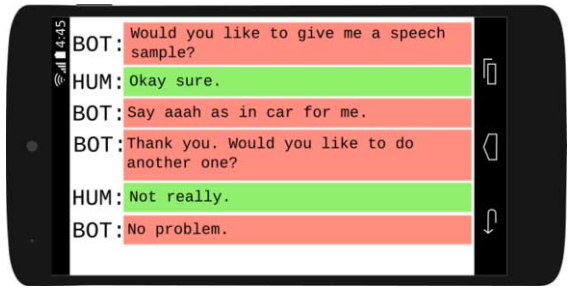

Figure 2. Simple speech assessments can be conducted by asking the user to provide a speech sample which is analysed for fundamental frequency and formants and stored in the database.

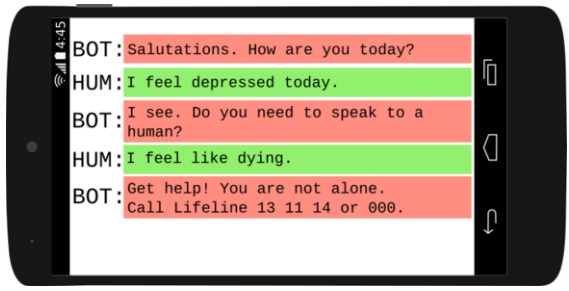

Figure 3. In response to user phrases that indicate depressive or suicidal thoughts, the chat-bot encourages the user to seek help.

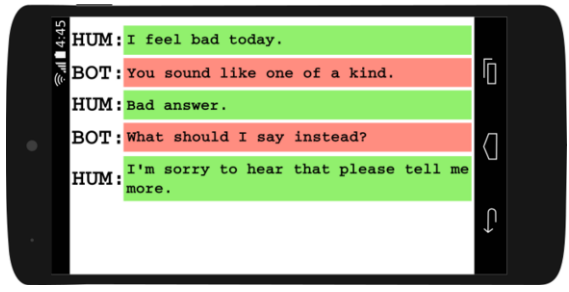

Figure 4. Where the first response is inappropriate, the chat-bot can learn, and permanently store, a new response.

3. Discussion

This paper has shown a summary of a preliminary chat-bot system developed for PWP. It seeks to ask relevant questions about the well-being of the particular user, provides exercise encouragement, speech assesments and general conversation. The system is expected to evolve over time as the chat-bot application is prototyped with a population of PWP.

The chat-bot addresses various aspects of PD. Speech degeneration is assessed with common speech assessments; frustration over speech flow is likely to be reduced in conversation with a machine, rather than a human and in severe cases the need for speech can

be circumvented by using the keyboard functionality. Motor symptoms such as tremor are monitored and ballistic movement encouraged. The affective symptoms of PD are also addressed with the chat-bot sensitive to phrases indicative of negative mood. The effect of medication and the progression of the disorder through the development of new symptoms can be recorded. Finally the ability to learn appropriate responses ensures that the chat-bot will be able to engage the user in conversation as well as performing a role in disease management.

This work demonstrates that an artificial conversational agent that mimics human conversation can be realized using contemporary technology. Furthermore, given the practical and beneficial uses of the chat-bot, it will likely play a role in the next generation of speech and communication therapy for PWP and other related speech disorders.

References

[1] N. Miller, E. Noble, D. Jones, D. Burn, *Life with communication changes in Parkinson's disease*, Age and Ageing 35(3):235-239 Epub 2006

[2] D. Robertson, *Maintaining the art of conversation in Parkinsons disease*. Age Ageing 2006 35: 211

[3] S. Sapir, A.A. Pawlas, L.O. Ramig *et al.*, *Voice and speech abnormalities in Parkinson disease: Relation to severity of motor impairment, duration of disease, medication, depression, gender and age*, J Med Speech-Lang Pathol 2001;9:213-26

[4] K. Forrest, G. Weismer, G.S. Turner, *Kinematic, acoustic, and perceptual analyses of connected speech produced by parkinsonian and normal geriatric adults.*, J Acoust Soc Am. 1989 Jun;85(6):2608-22.

[5] C. Saldert, U. Ferm, S. Bloch. *Semantic trouble sources and their repair in conversations affected by Parkinsons disease*, International Journal of Language & Communication Disorders 2014;49(6):710-721. doi:10.1111/1460-6984.12105.

[6] J. Liddle, D. Ireland, S.J. McBride, S.G. Brauer, L.M. Hall, H. Ding, M. Karunanithi, P.W. Hodges, D. Theodoros, P.A. Silburn, H.J. Chenery, *Measuring the lifespace of people with Parkinson's disease using smartphones: proof of principle*, JMIR Mhealth Uhealth. 2014 Mar 12;2(1):e13

[7] J. Weizenbaum, *ELIZA—a computer program for the study of natural language communication between man and machine*, Communications of the ACM, 9(1), 36-45. doi:10.1145/365153.365168

[8] A. Watson, T. Bickmore, A. Cange, A. Kulshreshtha, J. Kvedar *An internet-based virtual coach to promote to physical activity adherence in overweight adults: randomized controlled trial*, J. Med Internet Res. 2012 Jan-Feb 14(1)

[9] T. Bickmore, A. Gruber, R. Picard, *Establishing the computer-patient working alliance in automated health behavior change interventions*, Patient Education and Counselling 2005 Oct;59(1):21-30.

[10] R. Crutzen, G.Y. Peters, S. D. Portugal, E. M. Fisser, J.J Grolleman, *An Artificially Intelligent Chat Agent That Answers Adolescents' Questions Related to Sex, Drugs, and Alcohol: An Exploratory Study*, Journal of Adolescent Health , Volume 48 , Issue 5 , 514 - 519

[11] R. Wallace, *The Elements of AIML Style*, ALICE A.I. Foundation, 2001

[12] V. S. Kostic, T. Pekmezovic, M. Jecmenica-Lukic, T. Stojkovic, V. Spica, M. Svetel, E. Steganova, I. Petrovic, and E. Dzoljic, *Suicide and suicidal ideation in Parkinson's disease*, Journal of the Neurological Sciences, Volume 289, Issues (1-2), 15 February 2010, Pages 40-43

[13] Lifeline Australia, [online] `https://www.lifeline.org.au`, Last Accessed: 12/03/2015

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-134

The Relationship between Using Electronic Health Records and Meeting Accreditation Standards for Client Safety in Residential Aged Care Homes

Tao JIANG and Ping YU
School of Computing and Information Technology, University of Wollongong, Wollongong, 2522, NSW, Australia

Abstract. This study aims to identify the benefits of using electronic health records (EHR) for client safety in residential aged care (RAC) homes. The aged care accreditation reports published between 27 April 2011 and 3 December 2013 were downloaded and analysed. It could be seen from these reports that only 1,031(37.45%) RAC homes in Australia had adopted an EHR system by 2013. 13 RAC homes failed one or more accreditation standards. Only one of these was using an EHR system and this one met the accreditation standards on information systems. Our study provides empirical evidence to suggest that adopting and using EHR can be one of the effective organisational mechanisms to meeting accreditation standards in RAC homes.

Keywords. Electronic health records, EHR, nursing documentation, safety, risk, residential aged care, long term care, nursing home

Introduction

According to the International Organisation for Standardisation (ISO), EHR is a repository of patient data in digital form, stored and exchanged securely, and accessible by multiple authorised users. It contains retrospective, concurrent, and prospective information and its primary purpose is to support continuing, efficient and quality integrated healthcare [1]. Many residential aged care (RAC) homes have introduced electronic health record (EHR) systems [2] to standardise the structure and process of nursing documentation in order to improve the quality and efficiency of documentation, to comply with nursing and accreditation standards and to meet legal requirements [2].

Although there appears to be a high potential for EHR to contribute to improving client safety in aged care, empirical evidence is required in order to validate this claim. Previous studies have found a number of benefits of EHR, which may indirectly contribute to resident safety [3-6]: They can provide healthcare workers with faster access to enter data and retrieve health information than traditional paper based records [7], a benefit that is particularly useful in emergency situations [5]. They can improve communication between nurses and residents and among care staff, facilitate compliance with nursing procedure and improve efficiency in information management and education [2]. An EHR system that integrates decision support functions and

guidelines can provide support for treatment and care [7]. It can also provide easy access to test results in order to alert nurses to possible risks to residents' health [8]. An EHR system with an alert function about adverse drug interactions can reduce medication errors [9]. This study aims to provide the empirical evidence necessary to validate the relationship between EHR and client safety.

The Australian government implements its accreditation system through the Aged Care Standards and Accreditation Agency, Ltd, an Australian company limited by guarantee by the Minister for Mental Health and Ageing [10]. Accreditation is the internationally recognised evaluation process used in many countries to assess the quality of care [10]. Accreditation reports provide a relatively comprehensive and authoritative coverage of the performance of a RAC home by auditing whether the aged care services in the home meet the safety standard established by the Australian government [11]. The accreditation standards in Australia are detailed in the Quality of Care Principles 1997 [10]. According to the Australian Institute of Health and Welfare, the definition of safety is "avoidance or reduction to acceptable limits of actual or potential harm from healthcare management or the environment in which healthcare is delivered" [12]. Homes which want to pass aged care accreditation are required to have: effective information management systems, accurate and appropriate or required information, timely information, monitoring mechanisms, an evaluation system to monitor changes, and an appropriate care plan. It must be able to identify gaps in resident care and/or in the communication process [11]. As these factors are all related to client safety, this enabled this study to use the results of aged care accreditation reports as indicators as to whether the aged care services in a RAC home are safe or not.

1. Materials and Methods

This study takes the approach of secondary research using the published aged-care accreditation reports at the website of the Aged Care Accreditation Agency (www.accreditation.org.au). The primary accreditation reports were produced between 27 April 2011 and 3 December 2013.

In order to identify whether a RAC home had one or more items which failed to meet accreditation standards, the key words 'not met' were used to search each report. In order to identify whether a RAC home used EHR or not, the following key words were used in Section 1.8. Information Systems. In the documents a RAC home submitted to the Accreditation Agency the search terms used were: 'electronic clinical plan', 'electronic clinical documentation', 'electronic clinical information', 'electronic documentation', 'electronic care plan', 'electronic care documentation', 'electronic care information' and 'electronic health record'.

In order to aggregate the information, the reports were grouped into four categories: met all the standards and used EHR, met all the standards but did not use EHR, did not meet the standards but used EHR, and did not meet the standards and did not use EHR.

A chi square test was used to identify whether there was a statistically significant difference in meeting accreditation standards among the above four groups of RAC homes. SPSS version 21.0 (SPSS inc., Chicago, IL, USA) was used to conduct the analysis. A detailed in-text analysis was conducted on the RAC homes that did not meet one or more accreditation standards.

2. Results

2.1. The Difference in Meeting Accreditation Standards between the RAC Homes that Used an EHR System and Those which Only Used Paper Records

2,741(99.5%) of the 2,754 RAC reports which were audited by the accreditation agency during the period of January 2 to December 3, 2,013 met the 44 accreditation standards. Of them, 1,031(37.4%) used an EHR system for client health and personal care information management. The remaining 1,710(62.59%) used paper for information management.

Only 13 (0.5%) RAC homes failed to meet one or more accreditation outcomes, and only one (7.7%) of these 13 RAC homes used an EHR system for client health and personal care information management. The remaining 12 (92.3%) of the 13 RAC homes relied on paper-based systems. The result of a Pearson Chi-Square test shows that the RAC homes that had EHR in place were significantly more likely to meet accreditation standards than those that did not ($p = 0.026$). This evidence supports the claim that EHR can contribute to meeting aged care accreditation standards.

2.2. The Accreditation Outcomes that the RAC Home that Used EHR Fail to Meet and the Reasons for the Failure

Although the only RAC home using an EHR system failed to meet more than one accreditation outcomes, it did not fail in information systems, but in Accreditation Outcome 1.6 Human Resource Management and Outcome 2.4 Clinical Care.

The reason for the first failure was that the management had difficulty replacing staff on sick-leave or absence, causing a lack of adequately and appropriately skilled and qualified staff. The reason for the second failure might also relate to their deficiency in human resource management because of a lack of effective mechanisms to monitor staff work practices.

2.3. The Accreditation Outcomes that 12 RAC Homes that Only Used Paper Records Failed and the Reasons for the Failure

Of the 12 RAC homes that used paper records, nine failed in Accreditation Outcome 1.8 Information Systems. Six failed in 2.4 Clinical Care, 2.7 Medication Management, or 2.13 Behavioral Management. Five failed in 2.8 Pain Management or 2.10 Nutrition and Hydration. There were also six homes which failed in 1.6 Human Resource Management.

The three homes that failed to meet certain accreditation outcomes but met the standard on information systems all failed 2.13 Behavioral Management. In addition, one home failed other two outcomes: 2.4 Clinical Care and 2.8 Pain Management.

For the nine RAC homes that failed Accreditation Outcome 1.8 Information Systems, five also failed in 1.6 Human Resource Management, or 2.4 Clinical Care, or 2.7 Medication Management, or 2.10 Nutrition and Hydration, or 2.13 Behavioral Management. Four homes failed in 2.8 Pain Management.

The reasons for these failures are a lack of effective information management, accurate, appropriate or required information, and inappropriate care planning. The required information was not provided in time. A lack of an effective evaluation system fails to monitor changes in residents' health status in time. One home did not complete

incident reports, or failed in monitoring mechanisms and audit systems. Some homes could not identify gaps in resident care or communication process failure.

2.4. The Inferior Practices Identified for the RAC Homes that Used an EHR System and Met the Accreditation Standards

1,030 RAC homes that used an EHR system did meet age care accreditation standards. Three (0.29%) of these homes, however, received negative comments about performance. One of them was requested to develop and implement effective monitoring systems, suggesting the usage of EHR did not automatically improve the monitoring mechanism in a RAC home. Some inferior practices were identified in RAC homes that used paper records and met the accreditation standards.

There were 1,698 RAC homes which used paper records and met aged care accreditation standards. Ten of these homes, however, were requested to improve their monitoring mechanisms. It appears that more RAC homes (0.58%) that used paper did not have effective monitoring mechanisms than their peers which used an EHR system (0.10%). The possible reason is that the 'alert' functions in the common commercial EHR systems designed for RAC can effectively remind the nursing staff about the timeline for the re-assessment of healthcare needs of a resident and the development of new care plans. This overcomes the challenges in monitoring residents' health status and does so better than paper-based systems.

3. Discussion

This research has synthesised the results of 2754 accreditation reports published between 27 April 2011 and 3 December 2013 in order to identify the potential relationship between use of EHR and resident safety. We found that EHR systems had already been adopted as information systems by 37.4% of RAC homes in Australia by 3 December 2013. The RAC homes which had adopted EHR were significantly less likely to fail the accreditation standards. This provides the empirical evidence to support our proposition that EHR contributes to resident safety.

Paper-based nursing documentation is time-consuming and records are often illegible. Often, data must be entered several times, and this has the potential to cause inconsistency and/or error. It is also not easy to retrieve or update such data. Such difficulties have been identified as a major cause of stress and dissatisfaction among nurses in aged care [1]. These challenges might also be the root cause for the failed performance in information management by the RAC homes that used a paper-based information system. For example, inaccurate and inappropriate information might be caused by inadequate information capture, which would hinder nursing judgment and cause inappropriate care planning. The substantially better performance in aged care accreditation by RAC homes that used EHR suggests that many problems associated with paper-based records can be resolved by the use of well-designed EHR systems.

The literature shows that EHR systems have great potential to mitigate or avoid risk factors and enhance client safety [3-6]. For example, the ability to quickly enter and retrieve data at multiple computers scattered over an aged care facility will motivate busy nursing staff to enter more data [1], and this will lead to an improvement in the accuracy and timeliness of information. This will again lead to an information system that can provide more accurate feedback, and improve communication among

care staff. An alert in an EHR system can remind nursing staff of changes in resident status and help them to follow up with these changes. These benefits will obviously facilitate compliance with nursing procedure and improve efficiency in information management and education.

The limitation of this study was the nature of any secondary study, with all the findings drawn from analysis of Aged Care Accreditation reports. We can only identify information about whether an EHR system was used in a RAC home in the accreditation reports, but we cannot ascertain the nature and extent of usage of the EHR system by nursing staff. As only 13(0.5%) of the RAC homes failed the accreditation standard, the relationship between the use of EHR systems and the quality of aged care services cannot be determined by evidence collected from this information source alone.

4. Conclusion

There is a paucity of research evidence on the impact of EHR on the performance of RAC homes. By synthesising the accreditation results of 2,754 RAC homes between 27 April 2011 and 3 December 2013, this study has proved that the use of EHR can improve the opportunity for a RAC home to meet accreditation standards for information systems. Although the quality of aged care is determined by strategies used in many different areas of the home, our research suggests that the use of EHR can contribute greatly to quality care.

References

[1] P. Yu, D.M. Hailey, N. Wang, and D. Oxlade, Developing approaches to measure the quality of electronic versus paper-based nursing documentation in aged care homes. 2009.
[2] N. Wang, P. Yu, D. Hailey, and D. Oxlade, Developing measurements of the quality of electronic versus paper-based nursing documentation in australian aged care homes. Electronic Journal of Health Informatics **6 (1)**(2011), 1-6.
[3] S. Bourgeois and U. Yaylacicegi, Electronic health records: Improving patient safety and quality of care in texas acute care hospitals. International Journal of Healthcare Information Systems and Informatics **5**(2010), 1.
[4] F.R. Elevitch, Snomed ct: Electronic health record enhances anesthesia patient safety. AANA journal **73**(2005), 361.
[5] K. Malloch, The electronic health record: An essential tool for advancing patient safety. Nursing outlook **55**(2007), 159-161.
[6] D.F. Sittig and H. Singh, Electronic health records and national patient-safety goals. The New England journal of medicine **367**(2012), 1854.
[7] Y. Zhang, P. Yu, and J. Shen, The benefits of introducing electronic health records in residential aged care facilities: A multiple case study. 2012.
[8] A. Kutney-Lee and D. Kelly, The effect of hospital electronic health record adoption on nurse-assessed quality of care and patient safety. The Journal of nursing administration **41**(2011), 466-472.
[9] S.J. Ellner and P.W. Joyner, Information technologies and patient safety. The Surgical clinics of North America **92**(2012), 79.
[10] A.C.S.a.A. Agency, Accreditation standards. (2013).
[11] A.A.C.S.a.A. Agency. Accreditation overview. 2013; Available from: http://www.accreditation.org.au.
[12] A.I.o.H.a. Welfare. Definitions of safety and quality of health care. 2015; Available from: http://www.aihw.gov.au/sqhc-definitions/.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-139

A Pilot Study to Improve Access to Eye Care Services for Patients in Rural India by Implementing Community Ophthalmology through Innovative Telehealth Technology

Sheila JOHN [a,1], M PREMILA [a], Mohd JAVED [a],
Vikas G [a] and Amol WAGHOLIKAR [b]
[a] *Department of Teleophthalmology, Medical Research Foundation, Sankara Nethralaya, Chennai, India*
[b] *The Australian e-Health Research Centre, CSIRO, Brisbane, Australia*

Abstract. Objective: To inform about a very unique and first of its kind telehealth pilot study in India that has provided virtual telehealth consultation to eye care patients in low resource at remote villages. **Background:** Provision of Access to eye care services in remote population is always challenging due to pragmatic reasons. Advances in Telehealth technologies have provided an opportunity to improve access to remote population. However, current Telehealth technologies are limited to face-to-face video consultation only. We inform about a pilot study that illustrates real-time imaging access to ophthalmologists. Our innovative software led technology solution allowed screening of patients with varying ocular conditions. **Methods:** Eye camps were conducted in 2 districts in South India over a 12-month period in 2014. Total of 196 eye camps were conducted. Total of 19,634 patients attended the eye camps. Innovative software was used to conduct consultation with the ophthalmologist located in the city hospital. The software enabled virtual visit and allowed instant sharing of fundus camera images for assessment and diagnosis. **Results:** About 71% of the patients were found to have Refractive Error problems, 15% of them were found to have cataract, 7% of the patients were diagnosed to have Retina problems and 7% of the patients were found to have other ocular diseases. The patients requiring cataract surgery were immediately transferred to city hospital for treatment. Software led assessment of fundus camera images assisted in identifying retinal eye diseases. **Conclusion:** Our real-time virtual visit software assisted in specialist care provision and illustrated a novel tele health solution for low resource population.

Keywords. Telehealth, Ophthalmology, Mobile Eye care services, remote population, low resource settings

Introduction

Approximately 285 million people worldwide live with visual impairment [1]. Of these, 39 million people are blind (defined as best corrected vision of less than 3/60 in the

[1] Corresponding Author: Sheila John, D.O., Department of Teleophthalmology, Sankara Nethralaya, Medical Research Foundation, New No. 41, Old No. 18, College Road, Chennai 600006, India; Email: sheilajohn24@gmail.com.

better eye), and low vision in approximately 117 million people is due to uncorrected refractive errors [2]. 80% of global blindness is avoidable. One in every three treatable blind people in the world is an Indian. The number of blind persons in India is currently over 18 million and this estimate is 50% more than the figure of 12 million from a decade ago. It amounts to approximately one-fourth of all the blind people worldwide making the Indian blind population account for 20% of blindness [3]. Cataract is still the major cause of avoidable blindness in India. Taking the existing prevalence rate into account, it may be difficult to achieve total elimination of blindness in India by 2020. The recent epidemiological surveys have shown that Cataract, diabetic retinopathy, glaucoma, and childhood blindness have started to cause increased number of blind people in India. Hence, ophthalmology in India needs to be more holistic and medical initiatives towards all eye diseases should be taken. The high magnitude of avoidable blindness in India is concentrated in the rural areas mainly due to the lack of trained ophthalmologists being present in villages, underutilisation of public health services for the eye due to lack of awareness, lack of capital (from both government and public sector) for introducing facilities in the rural areas that can provide primary and secondary care for the eye and lack of adequately trained manpower. These problems can be addressed effectively by mobile, comprehensive and sustainable eye care systems easily accessible to the rural people in villages. Sankara Nethralaya (SN), a unit of Medical Research Foundation, is a tertiary eye care center in South India and is committed to patient care, ophthalmic research, and training at all levels for over three decades. With the aim of providing comprehensive and quality eye care to the rural population, a unique program implementing a mobile tele-ophthalmology unit was designed at SN and launched in 2003 [4]. SN conducts eye care camps in villages of South India. These remote outreach camps must ensure quality, especially in terms of screening vision threatening diseases, referral services, and affordable, rapid rehabilitation. However, subsequent interventions and follow up visits require the same medical records at multiple camp locations. To facilitate this, SN has implemented recording clinical data on electronic medical records (EMR). Teleophthalmology and EMR thus have unleashed a new frontier in ophthalmology for screening and recording of common ophthalmic diseases [5].

Teleophthalmology can reduce the need for travel for both the patient and ophthalmologist. The advances in internet technology and growth of internet across India's population have provided a tremendous opportunity to develop innovative Telehealth solutions [6, 7]. The trend of using video conferencing software solutions for tele-consultation is commonly observed [8]. However, these solutions require higher bandwidth and they also cannot provide real-time image sharing for point-of-care clinical diagnosis and treatment decision making. Therefore, the quality of Telehealth experience does not meet requirements for a clinical-grade consultation. We have addressed this very major limitation in the current state-of-the-art facility by developing an innovative Telehealth consultation service.

Our innovative software enabled service provides real-time fundus image sharing and annotation which allows a specialist ophthalmologist in the city hospital to examine and assess eye anomalies of patients in remote villages that have inadequate internet bandwidth. In this paper, we inform the results of our unique pilot study involving virtual visits during eye camps in low resource settings in villages in South India. Our pilot study suggests that improving access to eye care may facilitate in reducing the incidence of blindness in underserved as well as urban communities.

1. Methods

1.1. Identification of Remote Villages for Eye Camps

Remote Villages in Kanchipuram and Thiruvallur districts with a population of one million from the state of Tamil Nadu were chosen to provide comprehensive eye examination under the directives of the head of the department of Teleophthalmology at SN. The inclusion criteria for the villages considered factors such as distance from the base hospital being an important one (within150km to 200km) of the base hospital in Chennai, Prevalence of district-wise blindness as published by the District Blindness Control Society (DBCS) of India and Economic feasibility of the camp site. After the districts and villages were identified, the permission of the head of the DBCS was obtained in all states. The geographic locations of the villages are shown in Figure 1.

Figure 1. Eye camp locations and eye camp bus.

1.2. Conduct of Eye Screening Camps

This pilot study was conducted in eye screening camps in rural villages near Chennai, Tamilnadu from January 2014 until December 2014. The participating patients were from villages without adequate access to eye care services. The eye screening camps were conducted by a team composed of optometrists, social workers, administrative staff, ophthalmologists as well as information technology experts. This team travelled to the eye camp sites in a bus equipped with fundus camera, slit lamps and other instruments required for conducting eye screening examination. The patients underwent comprehensive eye examination by the team members to determine the prevalence of any ocular conditions. A hospital-based ophthalmologist advised patients through Tele consultations for further treatment. The specialist ophthalmologist consultation was carried out over video conferencing using data card and web-based

communication tools. A detailed ocular assessment was recorded using Electronic Medical Records. The work flow at the eye screening camps is shown in Figure 2.

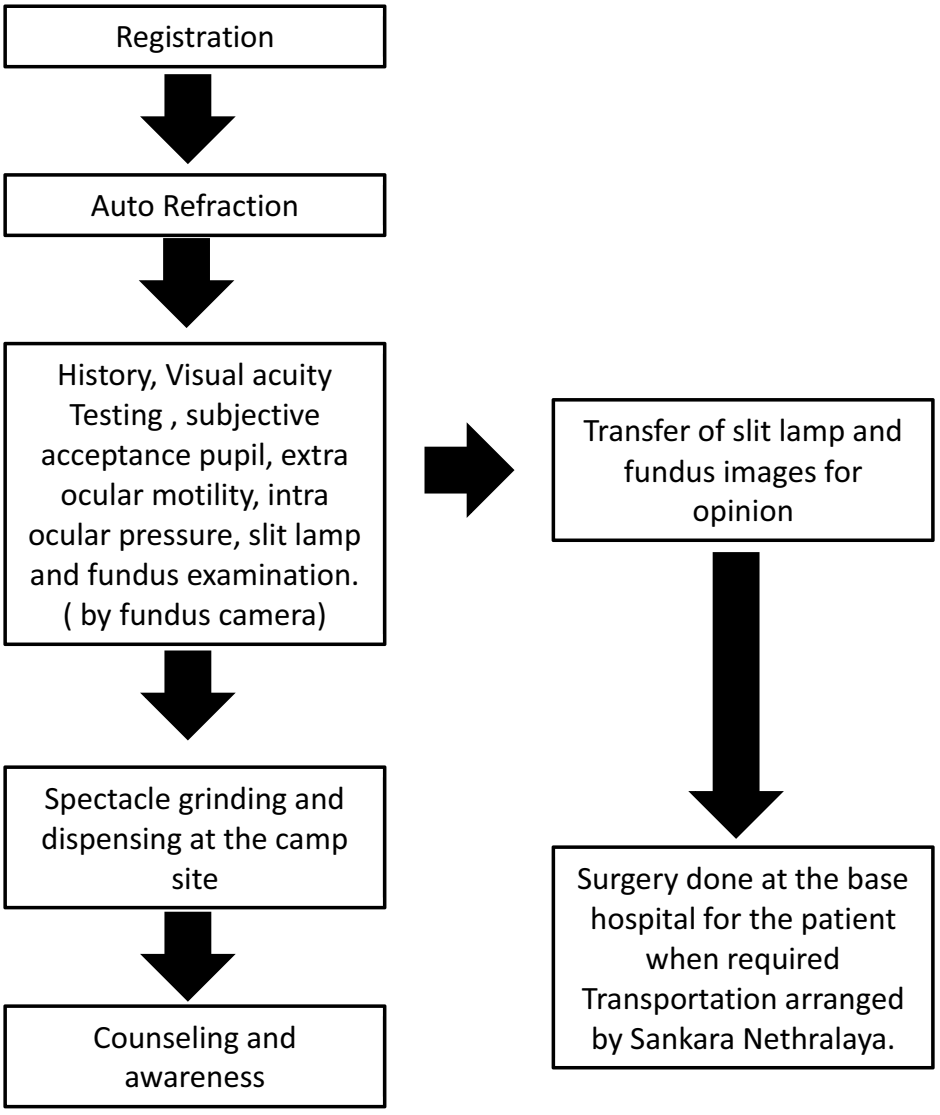

Figure 2. Tele Consultation flow chart.

1.3. Virtual Visit

An innovative software was used to share the fundus camera images in real-time. Since the software used accurate application-level sharing, there was no necessity to transfer images. A schematic representation and implementation of our solution used to conduct virtual visits is shown in Figure 3.

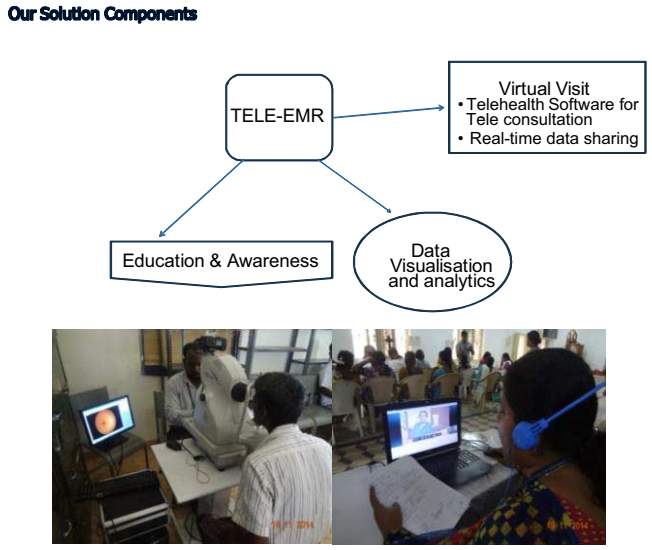

Figure 3. Schematic representation and implementation of our real-time virtual visit solution.

The ophthalmologist based at the city hospital could provide an immediate advice in real-time through the virtual consultation visit. All the patient records in the Tele-EMR were updated with the fundus camera images. The diagnosis of eye diseases is mainly based on eye images generated by the fundus camera. Therefore, automatic integration of the eye images with clinical notes at every visit and storing them into EMR will be very useful, especially in chronic diseases such as glaucoma, diabetic retinopathy and macular degeneration. Our solution enables seamless storing the eye images in the EMR and hence these images can be analysed for management of chronic eye diseases. The virtual visit component of our solution enabled sharing of fundus images with the ophthalmologist in the city hospital. The image sharing was implemented with a simple "click and share" feature. An exact replica of the fundus camera image appeared on the ophthalmologist's computer screen. The software's unique capability enabled real-time sharing of images in low bandwidth setting with weaker internet connectivity. Our solution thus addressed the limitations of technology infrastructure in rural regions of India where only allows satellite-based tele-connectivity is available with its implementation challenges. Our solution also simplified the work flow for telehealth consultation. The solution also required very little training to the eye camp site operators. The commercial-grade software was implemented without any development cost. Thus our model offers a cost-effective and efficient telehealth solution.

2. Results and Discussion

From January 2014 to December 2014 we have conducted 196 camps and a total number of 19,634 patients were examined. In our study 10073 males and 9561 females underwent comprehensive eye examination. The study shows a slightly higher percentage presence of male patients. About 51.3% of the patients in this study were males and 48.7% of them were females. The analysis of the results is shown in Figure 4.

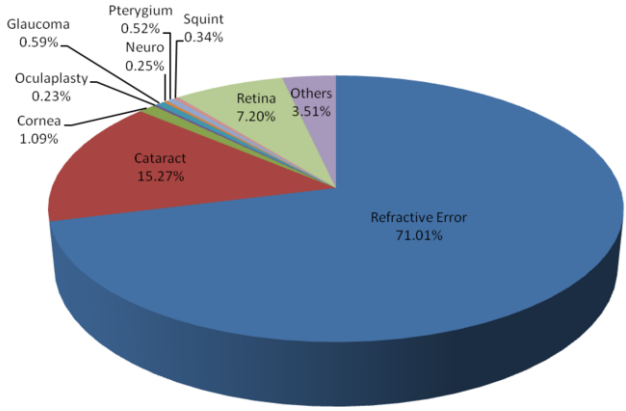

Figure 4. Analysis of patient diagnosis.

About 71% of the patients were having Refractive Error problems, 15% of them were found to have cataract, and 7% of the patients were detected with Retina problems [9] of which about 4% had diabetic retinopathy [10]. Seven (7) % of the patients had other ocular diseases and some of them were referred to the base hospital to undergo specific tests to confirm the diagnosis. Refractive errors included myopia, hyperopia and presbyopia for which glasses were dispensed at the eye camp location, as a corrective measure, with the help of mobile refraction van. All patients with significant cataract and other disorders requiring surgical intervention or other investigations as deemed fit after tele-consultation [11] were issued registration slips and advised to attend the appropriate subspecialty clinics at the base hospital at no cost. The software led diagnosis assisted in proactive assessment of patient's eye condition and resulted into immediate intervention to avoid any further deterioration of their eye health. About 1950 patients were referred to main hospital for cataract surgery during the study period and those patients underwent cost free state of art cataract surgery successfully at the SN community hospital. Our solution thus illustrates promising results for further development into a regular health service that can assist specialist clinicians with the ultimate benefit to the underserved population.

3. Conclusion

We conducted a pilot study that illustrated application of software led telehealth implementation to screen patients in low resource settings. Our pilot study showed that Virtual visit based eye care services can assist in identifying causes of blindness and avoidable blindness can be treated. A large scale commercial rollout of our solution can be considered for future implementation.

Acknowledgement

This pilot study has been supported by Sankara Nethralaya (SN), a unit of Medical Research Foundation with appropriate ethics approval. The author(s) sincerely thank Sankara Nethralaya and Medical Research Foundation for their support.

References

[1] Vision 2020 global initiative for the elimination of avoidable blindness: Action plan 2006–2011. Available at www.who.int/blindness/en/index.html (last accessed September 21, 2011).
[2] Dandona L, Dandona R. What is the global burden of visual impairment? BMC Med 2006;4:6.
[3] Online News Article, http://www.deccanherald.com/content/240119/india-accounts-20-per-cent.html, ^ April 2012.
[4] John S, Sengupta S, Reddy SJ, Prabhu P, Kirubanandan K, Badrinath SS. The Sankara Nethralaya Mobile Teleophthalmology Model for Comprehensive Eye Care Delivery in Rural India. Telemedicine and e-Health. 2012; 18: 382 – 7.
[5] Williams F, Boren SA. The role of the electronic medical record (EMR) in care delivery development in developing countries: a systematic review. Inform Prim Care. 2008; 16:139-45
[6] McKinsey & Company, Report, India's Internet opportunity, March 2013, Viewed online, May 2014.
[7] McKinsey & Company, Report, Online and upcoming: The Internet's impact on India, December 2012, Viewed Online, May 2014.
[8] Xiao, D., Vignarajan, J., Lock, J., Frost, S., Tay-Kearney, M.-L., & Kanagasingam, Y. (2012). Retinal image registration and comparison for clinical decision support. The Australasian Medical Journal, 5(9), 507–512. doi:10.4066/AMJ.2012.1364.
[9] Gupta A, Raman R, Sharma T Evaluation of the effectiveness of diagnostic & management decision by teleophthalmology for retinal diseases.. Indian J Med Res. 2014 Jun;139(6):954-5.
[10] Surendran TS, Raman R, Teleophthalmology in Diabetic Retinopathy, J Diabetes Sci Technol. 2014 Mar 17; 8(2):262-266
[11] Paul PG, Raman R, Rani PK, Deshmukh H, Sharma T, Patient satisfaction levels during teleophthalmology consultation in rural South India. Telemed J E Health. 2006 Oct; 12(5):571-8

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-146

Improving Video Based Heart Rate Monitoring

Jian LIN[a], David ROZADO[b], Andreas DUENSER[b]
[a] *School of Information Technol ogy and Electrical Engineering*
University of Queensland, Australia
[b]*CSIRO, Digital Productivity, Australia*

Abstract. Non-contact measurements of cardiac pulse can provide robust measurement of heart rate (HR) without the annoyance of attaching electrodes to the body. In this paper we explore a novel and reliable method to carry out video-based HR estimation and propose various performance improvement over existing approaches. The investigated method uses Independent Component Analysis (ICA) to detect the underlying HR signal from a mixed source signal present in the RGB channels of the image. The original ICA algorithm was implemented and several modifications were explored in order to determine which one could be optimal for accurate HR estimation. Using statistical analysis, we compared the cardiac pulse rate estimation from the different methods under comparison on the extracted videos to a commercially available oximeter. We found that some of these methods are quite effective and efficient in terms of improving accuracy and latency of the system. We have made the code of our algorithms openly available to the scientific community so that other researchers can explore how to integrate video-based HR monitoring in novel health technology applications. We conclude by noting that recent advances in video-based HR monitoring permit computers to be aware of a user's psychophysiological status in real time.

Keywords. Heart rate monitoring, Webcam, Psycho-physiology, Signal processing

Introduction

Cardiovascular pulse measurements have been utilized as a regular physiological signal in health studies for years. Resting heart rate (HR), as one of the typical factors, has been found to be associated with psycho-physiological status and cardiovascular disease mortality [6]. HR normally is obtained by taking a pulse manually and / or attaching special devices or electrodes to the subject (to the chest, wrist, finger, etc.). This can be inconvenient for the user in terms of movement restrictions and setup times or may require a break in task performance. Recently, various methods using non-contact, non-invasive devices to obtain pulse measurement have been developed with varying degrees of accuracy. Poh et al. [9] described a video-based method to measure HR by applying the Blind Source Separation algorithm on time series data. A different technique, Eulerian Video Magnification, was developed by [13] for the same purpose. Such contactless HR measurements may overcome some of the limitations and associated inconveniences present in other measurement tools that require some sort of physical contact. They offer exiting new ways of monitoring physiological signals with potential application areas ranging from medical applications to new ways of self-

monitoring. Similar to other emerging monitoring technologies such as gaze tracking [10], body gestures [3] or brain monitoring systems [2], video based HR or HR variability may be another useful tool for designing new health technologies and Human-Computer-Interaction paradigms. Furthermore, video cameras are relatively cheap and already available on many consumer devices.

The key methodology proposed by [9] uses each channel (Red, Green, and Blue) of the image from a video stream and processes it as an independent time-series signal. The algorithm used, Independent Component Analysis (ICA), reveals statistically independent source signals from the set of observations that are composed of linear mixtures of the underlying sources. The three RGB channels are treated as three independent signal sources. The output of ICA does not follow the order that it was fed in. In other words, the outcomes will be in random order and the hidden HR signal can be extracted out from the three components. The application of ICA in signal analysis is growing fairly quickly recently with numerous applications in EEG, speech recognition and other signal classification problems [4, 7, 12].

A recurrent problem of using the technique is the high level of noise in the source and the ICA derived signals. One technique for noise removal against false positives is the Kalman filter [5], which is a set of mathematical equations that provides an efficient recursive solution of the least-squares method. It provides estimations of past, present and future states, even without any prior information about the precise nature of the modeled system [11].

This work aims to investigate the performance of ICA in non-contact HR measurement using a video stream as suggested by Poh et al. [9], and to explore how to improve its accuracy and reliability by introducing several enhancements: skin color filter, raw data detrending and a Kalman filter into the methodology. By testing the different algorithms on actual video recordings, the performance of the original algorithm and our proposed modified methodology can be compared in a quantifiable way. Furthermore, an open-source application has been built for real-time measurement using the explored algorithm based in C++ and using the libraries OPENCV and QT[1].

1. Methodology and experimental design

The goal is to detect the HR of humans by monitoring and amplifying the hidden signal (blood flow) underneath the skin as captured by a webcam, and the region of interest is the human face. Therefore face detection and a skin color filter were implemented in this work for excluding the background and unwanted pixels in the frame. The time series of a captured video are stored in three channels (RGB), each channel is treated as a signal source and thus there are three signal sources as input for the independent component analysis algorithm. After being processed by the ICA algorithm, three new independent components are extracted out of the three RGB channels in random order. A frequency spectrum analysis is applied on each component and according to Poh et al. [9], the maximum amplitude of three components corresponds to the pulse of the subject. However, the result of this approach fluctuates considerably due to non-constant illumination or incomplete Fast Fourier transform, and the maximum amplitude component is not always the best estimator.

[1] https://github.com/PugKing1988/finetuning-bss-based-remote-pulse-measurement-method

Applying a Kalman filter in this methodology could improve the stability. It first generates estimates of the current state variables, along with their errors. Secondly, when the next measurement is computed or produced, these estimates are modified using a weighted average, which gives more weight to estimates with high certainty. Due to its recursive nature, the algorithm is able to run in real time using only two input parameters: one measurement from the previously calculated state, and one for the present measurement.

1.1. Pulse Measurement Improvement Methodology

First, our approach reads images from video-files or webcams (for real-time application) and then an automated face tracker is used to detect faces within the video frames and records the coordinates of the measured region of interest (ROI). We use the Open Computer Vision library to acquire the coordinates of the face location [8].

The ROI is then processed by a skin color filter which only allows certain skin color pixels to be collected. This is also implemented through the use of the OPENCV library. Furthermore, those three RGB traces are normalized. New traces are fed into a data detrending function, which helps to enhance signal strength and pulse detection.

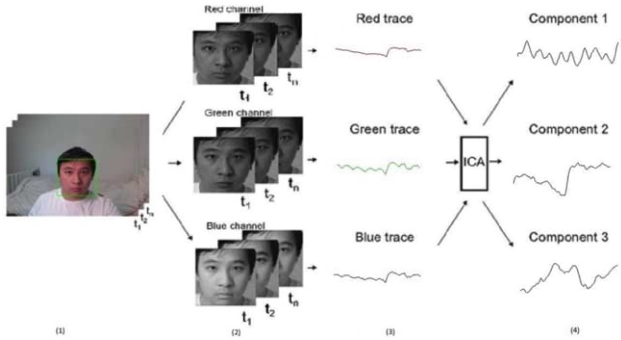

Figure 1: Pulse signal recovery method (1) The region of interest (ROI) is tracked with a face tracker (2) The ROI is separated into RGB channels and is normalized to obtain (3) the raw traces. Independent Component Analysis is applied on the normalized traces to acquire (4) three independent source signals

Independent Component Analysis is used on detrended traces to reveal the hidden signal which can be the subject's pulse [Figure 1]. We use the joint approximate diagonalisation of eigenmatrices (JADE) algorithm developed by Cardoso [1] to perform the ICA calculation. Since the output of ICA is in random order, the fast Fourier transform is performed on all of them to acquire three power spectra, the signal within the operational frequency range, which is 0.75 Hz with highest power density in each spectrum is recorded for each frame. The data are ranked in frequency from high to low and the pulse frequency is designated as the frequency with the highest power density among the top 20 points. This is derived from many observations of data scatter and called: pulse spectral maximum frequency-density selection (PSMFS).

Furthermore, a power density threshold is set to exclude false positive signals, which occurs frequently due to DC offset noise. It is set at 1.0 with a FFT size of 512 and another threshold is set for maximum change in pulse rate between successive measurements, which is taken 1 second apart. If the current pulse estimation has a power density less than 1, the difference between the current and the last computed value cannot exceed 7, or the current estimation will be rejected. Moreover, if the

power density exceeded 1, the difference between current and the last computed value cannot exceed 12, or the current measurement will be neglected and the system retains the last pulse measurement. A Kalman filter then is used once a successful measurement was detected to predict the next HR estimation.

1.2. Experiment Setup

The experimental system is based on a desktop computer (Dell Optiplex 990) and a webcam (Microsoft LifeCam HD-5000) for recording video streams of the user sitting in front of the computer. A commercially available Pulse Oximeter (Model CMS60D by CONTEC) served as ground truth data source. We used the external library OPENCV for image processing and QT for its professional GUI development tools.

For our experiments, we captured a 3-mintue long video of human faces using a webcam with 30 frames per second and 640*480 pixels for each frame.

15 participants (12 males, 3 females), aged of 20-35, were recruited for this study. All participants were seated in front of the computer at a distance of approximately 0.5 m from the external webcam sitting on top of the computer screen. The participants were asked to stay relatively still and focus on the screen to ensure the face detection routine worked throughout the recording. Meanwhile, the pulse oximeter, which samples at 60Hz, was clipped on the fingers of the participants to monitor and record the actual HR simultaneously with the captured video. The experiments were all conducted indoors and with a constant amount of luminescent light as the only source of illumination. In addition, 2 participants were asked to complete 5 more two-minute recordings right after some intense exercise. We refer readers to a video[2] showing the system performing HR estimation in real time.

2. Results

The different approaches for HR estimation are compared with each other. The original approach as proposed by Poh et al. [9] had the largest errors and the PSMFS approach outweighs the original approach by 0.86 bps [Figure 2]. The PSMFS approach with detrending function works even better than just the PSMFS by itself. We should also note that the PSMFS approach combined with all of the proposed improvements had the best performance, which obtained only 2.73 bps offset from actual pulse. To identify whether there is a significant difference between these methods, an ANOVA showed a significant difference between the different modalities ($F(5,84)=2.04$, $p < .01$). A post-hoc analysis (with Bonferroni adjustment) suggests that there is an improvement in the PSMFS approach with Kalman filter + skin color filter + detrending compared to the single PSMFS approach or the original approach.

False positives caused by DC offset need to be filtered out by setting a signal density threshold, which causes a delay on locking up the true HR. From now on, we refer to this independent variable (the delay) as latency. We compared accuracy and latency with different thresholds (from 1.0 to 2.5) for the PSMFS approach with all the modifications. The accuracy for each threshold was relatively close and an ANOVA revealed no significant difference between the approaches. However, the results for

[2] A video showing the real-time application: http://youtu.be/kHuX550DYD0

latency had a proportional relationship with the power density threshold. The lower the threshold is, the faster it locks into a pulse.

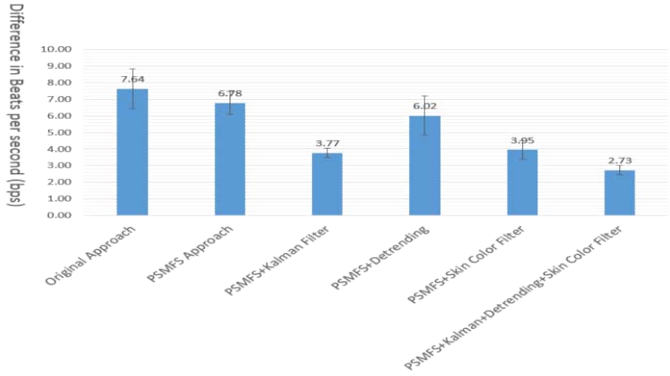

Figure 2: Average difference in beats per second between actual (as measured by a Pulse Oximeter) and estimated pulse for the different methods analyzed in this work.

The HR of people sitting quietly in front of a computer is usually in the range of 50-90 bpm. In order to test the performance of the algorithm to monitor HR of 100 bpm and higher, we measured the HR of two participants who had just completed intensive exercise in order to bring their HR up. The results of these pulse measurements were relatively poor and the average error in HR estimation exceeded 23.40 bps.

3. Discussion and Conclusion

As shown in [Figure 2], the original HR estimation method has the biggest difference in beats per second compared to the actual pulse. This was not expected because the original authors reported estimation within -0.05 bpm. An explanation for the lower performance of our implementation could be that in our case the blue component had two similar amplitude peaks at 0.75Hz and 1.03Hz within the operational frequency range. The actual pulse in the measurement was recorded as 73 bpm, and, according to the original approach, the designated pulse frequency was the peak at 0.75Hz. However, the correct pulse should correspond to the second peak at 1.03 Hz. A possible cause for this confusion may be the DC offset spectral frequency generated by the signal. It cannot be completely eliminated by using a band pass filter since the operational frequency range overlaps with the DC offset frequency range. It is worth pointing out that the original author used only natural light whereas our experiments were done in artificial light. Furthermore, the original authors also used a uniform white background for recording and we used a more cluttered background for all experiments.

Although the PSMFS approach with detrending and the original approach did not differ significantly, detrending had some effects in enhancing signal density. In certain videos, the 2.0 threshold was not exceeded at all throughout the experiment, however, by enabling the detrending function some signals reached levels above 2.0.

One limitation is that the webcam frame rate (30 fps) was relatively low, which requires at least 10 seconds to fill the FFT data array. If the light conditions are poor, the frame rate can drop to around 20 fps, which slows the process of filling up the FFT data array. Possible solutions for this problem are either to increase the sampling rate or decrease the size of FFT data array. Lowering the size of the FFT data array in theory

will decrease the accuracy because it will enlarge the beat difference between adjacent bins. On the other hand, increasing frame rate would require the use of a high-speed camera, limiting the applicability of this technique for low-cost applications.

One possible reason for poor HR estimation after intensive exercise may be fluctuations in pulse. Because the HR is slightly decreasing over time, the designated frequency is difficult to detect because the fast Fourier transform is filled with different frequency elements. Frequency smearing could easily occur as those frequency elements are adjacent to each other. As a result of this, most recorded data within one second can be totally distorted by one, two bins away or even more.

Our prototype method works best if the user sits still facing the camera. It tolerates some degree of movement and side facing but performance degrades if the user carries out excessive head movements. It needs at least 5 seconds of video feed to start carrying out reliable HR estimations. We tested the method in uncontrolled standard light and we did not empirically evaluate performance under different light conditions. As our method was designed in the context of developing new Human-Machine Interaction paradigms rather than developing clinical applications, current limitations such as reliability and limited accuracy for estimating elevated HR may be of less. Still, these limitations should be addressed in future work.

We have implemented and evaluated several methods of fine-tuning a blind source separation based remote pulse measurement methodology. Moreover, we have shown how this methodology can be implemented in a real-time application with a regular webcam. Overall, our proposed approach shows great potential for reliable, low cost, non-contact HR monitoring.

References

[1] Cardoso, J, 1998 Multidimensional Independent Component Analysis. In Proceedings of the 1998 IEEE International Conference on Acoustics, *Speech and Signal Processing*, 1998 Pp. 1941–1944 vol.4.

[2] Delorme, Arnaud, Tim Mullen, Christian Kothe, et al. 2011. EEGLAB, SIFT, NFT, BCILAB, and ERICA: New Tools for Advanced EEG Processing. *Intell. Neuroscience* 2011: 10:10–10:10.

[3] Gunes, Hatice, and Massimo Piccardi 2007. Bi-Modal Emotion Recognition from Expressive Face and Body Gestures. *Journal of Network and Computer Applications* 30(4). 1334–1345.

[4] James, Christopher J, and Christian W Hesse 2005 Independent Component Analysis for Biomedical Signals. *Physiological Measurement* 26(1): R15–39.

[5] Kalman, RE 1960 A New Approach to Linear Filtering and Prediction Problems. *Transactions of the ASME – Journal of Basic Engineering* (82 (Series D)): 35–45.

[6] Kristal-Boneh, E, H Silber, G Harari, and P Froom 2000 The Association of Resting Heart Rate with Cardiovascular, Cancer and All-Cause Mortality. Eight Year Follow-up of 3527 Male Israeli Employees (the CORDIS Study). *European Heart Journal* 21(2): 116–124.

[7] Lee, Te-Won, M.S. Lewicki, and T.J. Sejnowski 2000 ICA Mixture Models for Unsupervised Classification of Non-Gaussian Classes and Automatic Context Switching in Blind Signal Separation. *IEEE Transactions on Pattern Analysis and Machine Intelligence* 22(10): 1078–1089.

[8] Noulas, A. K., and B. J. A. Kröse 2006. EM Detection of Common Origin of Multi-Modal Cues. *Proc. 8th International Conf. on Multimodal Interfaces Pp. 201–208. ICMI '06.* New York, USA: ACM.

[9] Poh, Ming-Zher, Daniel J. McDuff, and Rosalind W. Picard 2010. Non-Contact, Automated Cardiac Pulse Measurements Using Video Imaging and Blind Source Separation. *Optics Express* 18(10): 10762.

[10] Rozado, David, Francisco Rodriguez, and Pablo Varona. 2010. Optimizing Hierarchical Temporal Memory for Multivariable Time Series. *Artificial Neural Networks–ICANN* 2010: 506–518.

[11] Welch, Greg, and Gary Bishop 1995. Chapel Hill, USA: University of North Carolina at Chapel Hill.

[12] Wisbeck, John Oersted, Allan Kardec Barros, Allan Kardec Barros Yy, and Renato Garcia Ojeda. Application of ICA in the Separation of Breathing Artifacts in ECG Signals. *The Fifth International Conference on Neural Information Processing, ICONIP'R98,* Kitakyushu, Japan, October 21-23, 1998,

[13] Wu, Hao-Yu, Michael Rubinstein, Eugene Shih, et al. 2012 Eulerian Video Magnification for Revealing Subtle Changes in the World. *ACM Trans. Graph*. 31(4): 65:1–65:8.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-152

Impact of Physician Community Structure on Healthcare Outcomes

Shahadat UDDIN [a,1], Margaret KELAHER [b] and Mahendra PIRAVEENAN [a,1]
[a] *Complex Systems Research Group, Faculty of Engineering & IT*
University of Sydney, Darlington, Australia
[b] *Melbourne School of Population and Global Health*
University of Melbourne, Parkville, Australia

Abstract. There is a substantial variation in healthcare spending and readmission rate for individuals having admissions to different hospitals. This study assessed how the community structure of physician collaboration networks that evolve during the period of providing healthcare services to hospitalised patients contribute to this variation. A physician collaboration network is said to have a community structure if the nodes (i.e. physicians) of that network can be easily grouped into sets of nodes such that each set of nodes is densely connected internally but sparsely connected between groups. This study constructed physician collaboration networks based on patient-sharing ties among physicians who provided healthcare services to hospitalised patients. An administrative health insurance claim dataset was utilised to extract patient-sharing ties among physicians. Simple linear regression models were estimated to assess the impact of the community structure of physician collaboration networks on the healthcare outcome measures (i.e. readmission rate and hospitalisation cost). From these models, this study found that the structure of a physician community has significant impact on readmission rate and hospitalisation cost. Healthcare administrators or managers could consider this finding in developing effective and efficient healthcare environments in their respective healthcare organisations.

Keywords. Physician community, physician collaboration network, healthcare outcome

Introduction

Networks evolve naturally among physicians during the course of providing healthcare services to patients. A collaboration network, for instance, emerges among physicians in course of treating a hospitalised patient, or a referral network evolves among physicians through referring patients to other physicians. Prior studies suggested that structure (e.g. how close physicians are to their colleagues and overall reachability between any pair of physicians) of such networks affects the quality of care received by patients and, in turn, their treatment outcomes [1, 2].

In the present healthcare literature, there are very few studies that follow network community approach to examine physician collaborations [3, 4]. For example, by following a network community method Landon et al. [4] recently analysed hospital-

[1] Corresponding Authors: Shahadat Uddin; Email: shahadat.uddin@sydney.edu.au; Mahendra Piraveenan; Email: mahendrarajah.piraveenan@sydney.edu.au.

based physician collaborations as means of selecting candidates for an Accountable Care Organisation (ACO). An ACO is a common platform of physicians in a specific locality that works within the framework of the current American fee-for-service system for the management of healthcare services and their associated incurred cost. However, these studies were based on a relatively small samples of physicians [3] or did not examine the physician community effect on healthcare outcomes [4]. In this study, we analysed physician collaboration networks in order to investigate how communities among physicians affect healthcare outcome measures. For identifying communities within physician collaboration networks, this study utilised a computational community detection algorithm.

This study used health insurance claim dataset to extract physician collaboration networks that emerged during the course of providing health services to hospitalised patients. Although electronic health insurance claim databases are mainly maintained for billing and administrative purposes, they are found useful in a wide range of healthcare research areas including analysing healthcare utilisation [5], measuring coordination performance of the hospital care network [6, 7], and comparing disease prevalence and drug outcomes [8]. In particular, this study considered claim information that described physicians who shared or visited common patients.

1. Research Method

A brief explanation of different social network terminologies utilised in this article (i.e. network, link or tie, node and community) has been illustrated in Figure 1.

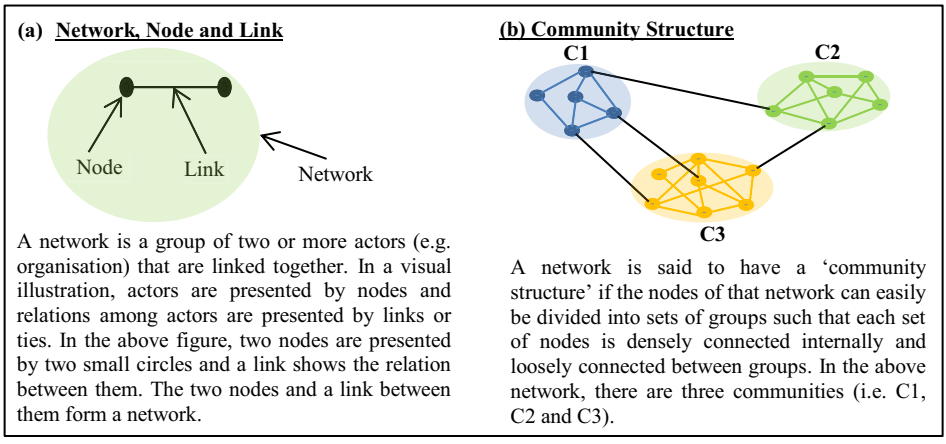

Figure 1. Illustration of basic social network terminologies utilised in this article.

1.1. Data Source

This study used 85 physician collaboration networks that had been evolved among physicians in 85 different hospitals during the course of providing healthcare services to hospitalised hip replacement patients. This dataset was provided by an Australian

not-for-profit health insurance organisation and contained physician-patient interaction information from January 2005 to February 2009. Before giving permission to use this dataset for research analysis purpose, this dataset was de-identified for privacy reasons by following a standard encryption algorithm. The usage of this dataset for research purpose was approved by the University of Sydney's ethics committee.

A hospital admission of a patient generates many physician claims submitted to the health insurance provider. These claims render details of services that had been provided by physicians during their visits to hospitalised patients. This study utilised these physician claims to count the number of patients shared by each pair of physicians and to create physician collaboration networks based on shared patients. The 85 physician collaboration networks considered in this study were constructed from 24,559 interactions between 2,229 physicians and 2,352 patients.

1.2. Constructing Physician Collaboration Networks

A physician collaboration network can be defined as a network that evolves among physicians as a result of providing treatment to common patients. It can therefore be thought as '*patient-sharing network among physicians*'. This study first identified patients visited by multiple physicians from physician claims submitted to the health insurance organisation. This information is then used to assign links between any pair of physicians for constructing the physician collaboration network in a specific hospital. If two physicians shared a common patient then this study assigns a link of weight one between them. An illustration of the construction of such a physician collaboration network is presented in Figure 2.

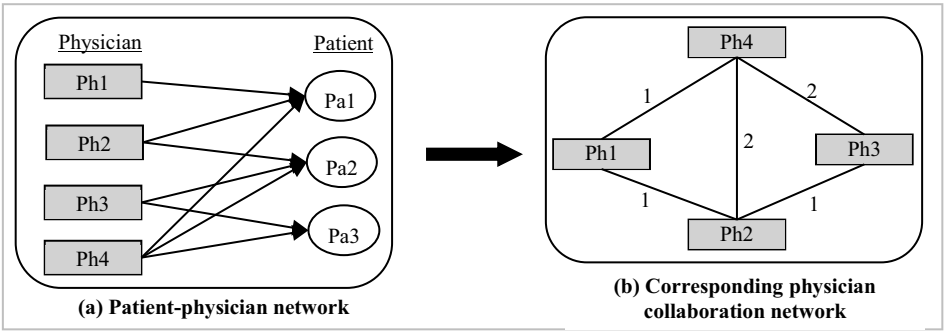

Figure 2. Construction of physician collaboration network. In a hospital (say *H1*), patient *Pa1* is visited by *Ph1*, *Ph2* and *Ph4* physicians, patient *Pa2* is visited by *Ph2*, *Ph3* and *Ph4* physicians, and physician *Ph3* and *Ph4* visit patient *Pa3*. This *patient-physician* network is depicted in the panel (a). The corresponding physician collaboration network for this *patient-physician* network is demonstrated in the panel (b). The number next to each link represents the number of shared patients between the corresponding physician nodes of that link.

1.3. Identifying Communities within Physician Collaboration Networks

In recent years, networks (e.g. physician collaboration networks) have been studied and developed in many areas of science including internet, power grids and food webs. One

of the main issues in modeling such networks is to extract hidden structures, called communities. Communities consist of entities, called nodes, and their relationships, called edges. They emerge as dense parts in a network while they may have a few relationships to each other. In order to uncover the community structure of each physician collaboration network, this study applied an algorithm introduced by Newman [9] and refined by Newman and Girvan [10]. This algorithm can detect groups within networks that share higher number of ties than would be expected by chance alone. This so-called modularity maximisation algorithm assigns each node to a single community. The number of links presented among the participating nodes in a network defines the census of communities and their sizes [9, 10]. In a physician collaboration network, communities are comprised of distinct and non-overlapping groups of physicians. The community detection process for a hospital from the research dataset of this study is depicted schematically in Figure 3.

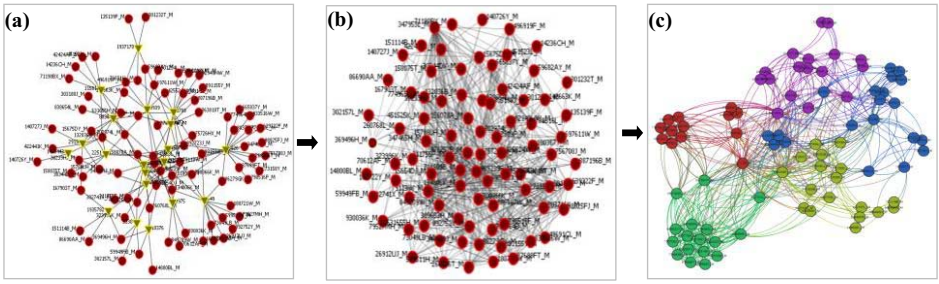

Figure 3. Community detection process from the physician-patient interactions for a hospital from the research dataset. The panel (a) represents the physician-patient interactions that evolve through physicians' visit to hospitalised patients. The red circle shapes represent physicians and the yellow triangular shapes represent patients. The panel (b) represents the corresponding physician collaborations network. In both of these panels, there are unreadable texts that represent system generated names for each patient and physician node. Lastly, the panel (c) represents the corresponding communities. Members of each of the 5 communities have been illustrated by identical colors.

The underlying interactions between patients and physicians shape a given physician collaboration network. In a physician collaboration network, a link between two physicians indicates that they have a common patient. In order to explore physician communities, this study therefore looked at network measures that captured structural attributes of communities (i.e. number of community and average number of node per community) and a statistical measure that took the underlying community membership statistics of physicians and patients under consideration (i.e. ratio between the number of physicians and patients in a physician collaboration network).

1.4. Healthcare Outcome Variables: Hospitalisation Cost and Readmission Rate

In calculating hospitalisation cost for a physician collaboration network, this study considered the average of hospitalisation costs for all patients, who belong to that physician collaboration network, extracted from their claim details. For a physician collaboration network, the readmission rate represents the ratio of patients (in percentage) who have hospital admissions (for the same medial reason) more than once

within a period of 28 days after discharging from hospitals for their initial/first hospital admissions.

2. Results

On average, there are 4.25 communities noticed in each physician collaboration network. The range is between 2 and 7 (SD = 1.24). The average of hospitalisation cost is $24,009 and ranged from $13,926 to $622,193 (SD = 9596). For the readmission rate, the average value is 11.64% and ranged from 0 to 67% (SD = 12.79). The descriptive information about the research dataset is provided in Table 1.

Table 1. Descriptive statistics about physician collaboration networks.

	Average	Range	Standard deviation
Communities per physician collaboration network	4.25	[2 – 7]	1.24
Number of physician per community	13.42	[3.2 – 37.8]	6.96
Ratio of the number of physicians and patients	3.17	[0.74 – 6.79]	1.44
Readmission rate (%)	11.64	[0 – 67]	12.79
Hospitalisation cost ($AUD)	$24,009	[$13,926 - 622,193]	9596

An increase in the number of communities in each physician collaboration network is associated with the lower readmission rate. If there emerges higher number of communities in a physician collaboration network then there is a higher chance that patients belonging to that network will have lower readmission rates. The result from a simple linear regression model is presented in Table 2.

In contrast, the average number of nodes (i.e. physicians) per community has a positive influence on the readmission rate. The outcome from a simple linear regression model is presented in Table 2. The physician communities having higher members will drive the readmission rate affirmatively and vice versa.

We noticed that the ratio between the number of physicians and patients in a physician collaboration network has a positive impact on the hospitalisation cost. If the ratio is high then healthcare spending will be high and vice versa. The result obtained from a linear regression model is presented in Table 2.

Table 2. Linear regression models for checking relations between independent and dependent variables.

Model	Dependent Variable	R^2 Value	Intercept	Independent Variable	Coefficient	Sig.
1	Readmission rate	0.127	31.12	Number of community	-3.29	0.01
2	Readmission rate	0.077	8.81	Physician per community	0.41	0.04
3	Hospitalisation cost	0.323	19172.36	Ratio of physician and patient	1525.17	0.00

3. Discussion, Conclusion and Future Research Direction

This study found that hospitals with a higher number of physician communities have a lower readmission rate. This association reflects the ease of knowledge sharing regarding patient care among physicians who belong to the same community. According to the community detection method followed in this study, physicians are more connected (i.e. having more shared patients) with their peers working in the same community compared to their other peers who belong to other communities. This higher level of connectedness facilitates efficient and effective exchange of healthcare knowledge among physicians.

Hospitals with higher number of nodes (i.e. physicians) in their communities have higher levels of readmission rate. Member physicians of a large community need to retain higher number of relations with their colleagues compared to the member physicians of a small community. A larger community has higher number of members who are well-connected among themselves compared to a smaller community. Maintaining this greater number of relations has two possible consequences. First, physicians need to give an extra time and effort to maintain and continue these relations. Second, they may suffer from 'information overload' which refers to the difficulty experienced by a person in understanding an issue and making decisions that that can be caused by the presence of too much information [11]. Physicians may receive a large volume of information (i.e. receiving different information from their colleagues) or repetitive information (i.e. receiving same or similar information from their colleagues) from an increasing number of their colleagues.

This study constructed physician collaboration networks from the physician-patient interactions. Hospitals with higher number of physicians in these physician-patient interactions have increased levels of spending (i.e. hospitalisation cost). The presence of increased number of physician in a physician collaboration network may create redundant physicians visits to patients. Therefore, this association reflects the difficulty of care coordination as physicians have to manage information from an increasing number of their colleagues, which could be either a cause or an effect of increased healthcare utilisation.

In summary, this study demonstrated that structural characteristics of physician collaboration networks have significant impact on hospitalisation cost and readmission rate. This study provides some opportunities for future research. First, based on the presence of shared patients this study constructed physician collaboration networks from health insurance claim data. However, it cannot be known what information, if any, pass across the ties defined by shared patients. Further research can explore this by observing a real (i.e. not from the electronic claim data) physician collaboration network in hospitals. Second, unobserved moderating factors (e.g. patient age, comorbidity score and length of stay, hospital type, and casemix of both patient and hospital) could be considered to check whether they have any impact on the relation between physician community and healthcare outcome. Third, other dependent variables (e.g. patient satisfaction and hospital infection rate) could be taken under consideration. Finally, physician communities other than for hip replacement patients can be considered to check the generality of this study's findings.

References

[1] Uddin, S., Hamra, J., and Hossain, L., *Mapping and modeling of physician collaboration network*. Statistics in Medicine, 2013. **32**(20): p. 3539-3551.

[2] Barnett, M.L., Landon, B.E., O'Malley, A.J., Keating, N.L., and Christakis, N.A., *Mapping Physician Networks with Self‐Reported and Administrative Data.* Health Services Research, 2011. **46**(5): p. 1592-1609.

[3] Chory, H., Abboud, L., and Peled, R., *Reducing the Volume of Antibiotic Prescriptions: A Peer Group Intervention Among Physicians Serving a Community with Special Ethnic Characteristics*. J Manag Care Pharm, 2012. **18**(4): p. 324-28.

[4] Landon, B.E., Onnela, J.-P., Keating, N.L., Barnett, M.L., Paul, S., O'Malley, A.J., Keegan, T., and Christakis, N.A., *Using Administrative Data to Identify Naturally Occurring Networks of Physicians.* Medical care, 2013. **51**(8): p. 715-721.

[5] Friedman, D.S., Quigley, H.A., Gelb, L., Tan, J., Margolis, J., Shah, S.N., Kim, E.E., Zimmerman, T., and Hahn, S.R., *Using pharmacy claims data to study adherence to glaucoma medications: methodology and findings of the Glaucoma Adherence and Persistency Study (GAPS).* Investigative ophthalmology & visual science, 2007. **48**(11): p. 5052-5057.

[6] Uddin, S. and Hossain, L., *Social networks in exploring healthcare coordination.* Asia Pacific Journal of Health Management 2014. **9**(3): p. 53-62.

[7] Uddin, S., Hossain, L., Hamra, J., and Alam, A., *A study of physician collaborations through social network and exponential random graph.* BMC health services research, 2013. **13**(1): p. 234-247.

[8] Wennberg, J.E., Roos, N., Sola, L., Schori, A., and Jaffe, R., *Use of claims data systems to evaluate health care outcomes.* JAMA: Journal of the American Medical Association, 1987. **257**(7): p. 933-936.

[9] Newman, M.E., *Fast algorithm for detecting community structure in networks.* Physical review E, 2004. **69**(6): p. 066133.

[10] Newman, M.E. and Girvan, M., *Finding and evaluating community structure in networks*. Physical review E, 2004. **69**(2): p. 026113.

[11] Jacoby, J., *Perspectives on information overload.* The Journal of Consumer Research, 1984. **10**(4): p. 432-435.

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-159

Educating the Health Informatics Professional: The Impact of an Academic Program

Sue WHETTON [a] and Cherie HAZLITT [b]
[a] *University Department of Rural Health, Tasmania*
[b] *Department of Health and Human Services, Tasmania*

Abstract. Introduction: The successful implementation and utilisation of electronic health information systems is dependent on a highly knowledgeable and skilled workforce. In Australia there is a range of education and training opportunities that seeks to meet these workforce needs. This range of programs reflects both the multi-disciplinary characteristic of health informatics and its wide application within the healthcare environment. We need to discuss the role of each program or type of program in developing a skilled and knowledgeable workforce, and in expanding the knowledge base of the discipline. This paper contributes to such a discussion by describing a pilot study that focused specifically on the role/impact of the University of Tasmania academic health informatics program. **Methods:** The study comprised an anonymous on-line survey followed by a small number of interviews. The online survey included closed questions which gathered quantitative data about Quantitative data were analysed using appropriate numerical methods such as response counts and/or percentages. Open-ended questions were analysed using thematic analysis. **Results:** Qualitative data indicated that course graduates reside in every state and territory, with the majority being employed by the various state health services. The majority of respondents had moved into health informatics professions or into senior positions in health informatics. Eighty percent attributed this directly to their participation in the course. Respondents indicated a strong socio-technical orientation in their approach to health informatics. **Discussion:** The program appears to be having an impact on the health informatics workforce, particularly in promoting a strong socio-technical focus. **Conclusion:** Evaluation of health informatics programs would enable the development of a comprehensive and complementary network of offerings that would meet the diverse needs for health informatics professionals in the healthcare and academic environment.

Keywords. Health informatics education, course impact, course evaluation

Introduction

The successful implementation and utilisation of electronic health information systems depends on a highly knowledgeable and skilled workforce. This workforce includes health informatics professionals together with the clinicians, managers and researchers who regularly use health information. It should also include academic health informaticians who contribute to research and the education of the profession. [1,]. In Australia a range of education and training opportunities seek to meet these workforce needs. Offerings include health informatics academic programs, health informatics

streams within other academic programs and health informatics content in related disciplines such as health information management, information systems and computing programs. Health informatics units are also offered in clinical, allied health and information management academic programs. Other pathways to achieving skills and knowledge include short health informatics courses and professional certification programs such as the recently introduced Certified Health Informatician Australasia (CHIA) program [2]. Appendix 1 gives an indication of the range of courses and programs currently offered. This range reflects both the multi-disciplinary characteristic of health informatics and its wide application within the healthcare environment. At the same time it contributes to a situation where 'there is no single recognised means of entry into the workforce, and no restrictions on entry beyond what an employer may specifically require' [3]. This lack of parameters creates questions around core knowledge and skills required of practicing health informaticians. The CHIA program seeks to establish parameters for entry into the workforce by 'seeking to ensure that health informatics professionals have a common core of knowledge and skills' [2]. The CHIA program may therefore be viewed as an entry point into the profession. However, it does not identify to the relationship between CHIA and other education and training programs. This is an interesting issues given that the educational criteria for entry into the CHIA program itself is 'any degree and does not have to be in health informatics' [2]. This raises questions, particularly for specific health informatics academic programs. Potential health informaticians may well ask 'Why do I need to do a health informatics degree/postgraduate degree, if any degree is accepted?' Answering these questions would explicate the relationship between academic qualifications and professional certification programs, while also differentiating between health informatics and related professions. There is a need for such a discussion [4, 5]. This paper contributes to such a discussion, reporting on a pilot study that tracked graduates and current students of the University of Tasmania post-graduate e-health (Health Informatics) courses to consider the role/contribution of academic health informatics programs. The aims of the study were to:

- Map the location of UTas health informatics graduates and current students in health services across Australia
- Map professional location of these graduates., differentiating between health professionals and health informatics professionals
- Explore the impact of the UTas program on graduates' approaches to the practice of health informatics

1. The Health Informatics Program

1.1. The Courses

The UTas Health Informatics program commenced in 2002 offering a Graduate Certificate and a Graduate Diploma. A Masters course was introduced in 2012. These courses emphasise knowledge and skill development for health informatics professionals and for health professionals wishing to enhance their understanding of health informatics. A Bachelor of Health Informatics (Professional Honours) was introduced in 2013. This course seeks to enhance health informatics research skills and provide a pathway into academic research opportunities. All courses are offered part-

time, on-line with no compulsory face-to-face component. This attracts enrolments from across Australia.

1.2. Approach to Health Informatics

The UTas program emphasises health informatics as a socio-technical discipline and profession. While health informatics is broadly represented as a socio-technical discipline, this is not always evident in academic or professional discussions. While it is acknowledged that the people and processes that comprise the social system are integral to health informatics, they are often discussed in the context of minimising resistance to the technological system and problems are formulated in terms of understanding and minimising this resistance in the immediate environment [6]. The UTas program views the socio-technical systems as extending beyond the immediate environment. 'Socio-technical systems at the local level will be influenced by broader economic, political and cultural systems and vice versa' [7]. In doing so, the program encourages students to critically explore cultural, economic, political and legal issues associated with the implementation of health information systems. In so doing the program aims to produce critical and reflective health informatics practitioners, teachers and researchers

2. The Study

2.1. Method

The study comprised an anonymous on-line survey followed by a small number of interviews. The online survey included closed questions which gathered quantitative data about the distribution of graduates across Australian health systems and health professions. Open-ended survey questions and interviews explored the effectiveness of the course in supporting health informatics careers and the influence of the content and focus of the course on the way graduates approached health informatics. All graduates and current students of the health informatics program were invited to participate. Participants were recruited via the university email system. The email was also sent to an alternative email where available. The email included an information sheet about the project and survey and a link to the survey website. Ninety emails were sent. Forty-seven were recorded as undelivered. It was therefore assumed that forty-three emails were delivered. Of these, twenty-four graduates/students (57%) completed the online survey. Seven respondents indicated their willingness to be interviewed.

2.2. Data Analysis

Quantitative data were analysed using appropriate numerical methods (such as response counts and/or percentages). Open-ended questions were analysed using thematic analysis. Thematic analysis suits questions related to people's views or perceptions [8, 9]. It was therefore considered appropriate for this study. The initial stages of the analysis involved an iterative reading of the survey responses and interview transcripts to identify recurring comments, phrases and terms. These were grouped into broad

categories or themes. The focus of this analysis was on explicit rather than implicit meanings in the text [10].

3. Results

3.1. Quantitative Results: Location of Graduates

The quantitative data provided information about the distribution of graduates across Australian health systems and health professions. University enrolment data indicates that students in the program reside in all states and territories in Australia. Survey respondents, although small in number, reflected this dispersion, with respondents residing in every state and territory. The majority were employed by the various state health services. One was employed by the Commonwealth Department of Health, one by a Medicare Local, three were employed by commercial companies and one was unemployed.

The data were analysed to identify any change in position since commencing the course. Participants who had changed they had changed employer/position were asked whether and if this represented a promotion. As Table 1 shows, prior to commencing the course, nine respondents were working in health informatics positions (shaded cells). After completing the course, a further five respondents had moved into health informatics positions. Twelve respondents reported that they had been promoted. This included seven who had previously been in health informatics positions and the five respondents who had moved into health informatics roles. It is noted that two respondents self-reported a promotion while using the same job title. Descriptions of roles suggested that while the job title remained the same, the scope of the positions had broadened. Overall, job titles and description pointed to many course participants being at the tactical and strategic planning level of departments and organisations.

Table 1. Pre and post course position/profession.

Pre-Course Profession/position	Post-Course Profession/position	Promotion
Administration	Health Informatics Lecturer	Y
Consultant Clinical Pharmacist	Informatics Pharmacist	Y
Health Librarian	Health Librarian	
Clinical Nurse Consultant Research Coordinator	Clinical Nurse Consultant Research Coordinator	
Sales & Accounts – CIS	Consultant	Y
Health Informatics	EHR Business System Manager	Y
Allied Health	Allied Health	
E-Health Support	E-Health Manager	Y
EMR Manager	EMR Manager	Y
Health Systems Coordinator	Human Machine Interface Development	
EHR Systems Project Officer	EHR Systems Project Officer	Y

Doctor	Doctor	
Medicine	Doctor	
Nursing	Clinical Systems Administrator	
Psychologist	Unemployed	
Nursing	Nursing	
ICT Advisor	ICT Strategic Advisor	Y
E-Health Policy	ICT Business intelligence	Y
Electronic Medical Record Trainer	Data Manager	Y
Physiotherapy	Senior Paediatric Physiotherapist	
Business Analyst	Assistant Director – Data Warehouse Environment	Y
Business Manager	E-Health Clinical Software and Secure Messaging	Y
Manager (Health Informatics)	Manager (Health Informatics)	

3.2. Qualitative Thematic Analysis

Thematic analysis of the open-ended survey questions and interviews explored participant perceptions of the effectiveness of the course in supporting health informatics careers and the influence of the socio-technical perspective on the way graduates implemented health informatics.

3.2.1. Impact of Course on Career

Respondents who had changed employer or positions were asked if they believed that their participation in the course had impacted on this change. Of the 14 who had changed positions, 12 (88%) answered yes. In analysing responses, one major theme and one minor theme were identified. The major theme attributed the change primarily to participation in the program. Respondents referred to the course providing them with a richer understanding of the domain of health informatics and the confidence to apply for promotion. The minor theme considered that participation in the course was one of several factors interacting to enable them to change. In addition, stated that he/she had accepted a role as the clinical representative for an e-health management group, which 'I would never have considered prior to the course'. These responses, while not negating the impact of other variables, do indicate that the UTas program is influencing career choices and progression of its graduates.

3.2.2. Impact of the Program on Graduates' Approach to Health Informatics Activities

Participants were asked how they felt involvement in the program influenced their ideas about health informatics. The analysis identified three distinct themes. One theme spoke of the course providing new and advanced skills and knowledge that participants applied at both the operational and strategic level. A second theme discussed the course

in terms of clarifying, structuring and consolidated existing understanding. This view was primarily expressed by respondents working in health informatics prior to commencing the course. A third theme focused on expectations about the potential of health informatics. Respondents spoke of the need to think critically about the potential and limitations of health informatics solutions. All three themes shared the belief that the course had given participants confidence to express their views and knowledge and to apply their skills.

3.2.3. Relevance of a Socio-technical Perspective

Participants were asked whether they cultural and organisational issues influenced the uptake of health informatics systems. This was intended to determine the extent to which they approached health informatics as a socio-technical discipline. All responses supported the need for a socio-technical orientation. Two complementary themes were identified. The first spoke of the need for strong leadership that promoted cultural change. The second reflected a more negative orientation, emphasising that a focus on the technology lack of understanding of cultural and organisational factors acted as a barrier to successful implementation of electronic information systems.

4. Discussion

The pilot study explored the role/impact of an academic health informatics education program by mapping the professional and geographical location of graduates and current students in health services across Australia and by exploring the impact of program on graduate's approach to the practice of health informatics. While the number of participants in the study was low, the results indicate that the program is having an impact on the health informatics workforce. This is indicated by the spread of graduates across all states and territories where they are increasingly taking up health informatics roles, adopting senior positions and contributing to the professional activities of health informatics organisations. The results also point to the success of the program in producing graduates who strongly advocate and seek to implement a socio-technical approach to health informatics.

While the results suggest that the program is successfully contributing to producing a skilled and knowledgeable workforce, several factors may have affected the study. The project, from initial planning to final report, was required to be completed within six months. This impacted on the capacity to recruit participants and conduct the face-to-face interviews. Finally, as with many surveys, hindsight pointed to questions that could have been asked. For example, during the interviews it became apparent that graduates are not only filling influential roles in the workplace but are also taking on roles such as membership of professional organisations. A question relating to this issue would have provided more insight into the influence of the program.

5. Conclusion

The successful implementation and utilsation of electronic health information systems is dependent on a highly knowledgeable and skilled workforce. A range of courses and

other initiatives seek to meet this need. It is important to consider the roles and contributions of these programs in developing not just a skilled and knowledgeable workforce but also the health informatics researchers and educators who build the knowledge base of the discipline. While there may be different views about relevance or appropriateness of various programs there has been little analysis to determine the role of each in the overall framework of health informatics education.

References

[1] Australian Health Ministers Advisory Council, National E-Health Strategy for Australia, Victorian Department of Human Services, on behalf of the Australian Health Ministers' Conference (2008)

[2] Certified Health Informatician Australasia website, 2015, http://www.healthinformaticscertification.com/

[3] Health Workforce Australia 2013 *Health Information Workforce Report*, http://www.industry.gov.au/industry/Office-of-the-Chief-Economist/SkilledOccupationList/Documents/2015Submissions/HIMAA-Attachment-4.pdf p 10.

[4] Covvey HD, Zitner D, Bernstein, RM (2001), 'Pointing the Way: Competencies and Curricula in Health Informatics' *Waterloo*, Ontario, Canada

[5] http://medicine.dal.ca/content/dam/dalhousie/pdf/faculty/medicine/departments/core-units/DME/medical-informatics/PointingtheWay.pdf

[6] Huang, QR, (2007), 'Competencies for graduate curricula in health, medical and biomedical informatics: a framework' Health Informatics Journal, 13 (2) 89-103

[7] Morris A. Socio-Technical Systems in ICT: A Comprehensive Survey. Technical Report DISI-09-054. Ingegneria e Scienza dell'Informazione, University of Trento 2009.

[8] Whetton, SG and Georgiou, A*, "Conceptual challenges for advancing the socio-technical underpinnings of health informatics", *Open Medical Informatics Journal*, **4** (1) pp. 221-224.

[9] Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 2013; 13**:**117

[10] Mills AJ, Durepos G, Wiebe E., *Encyclopedia of Case Study Research: L - Z; Index, Volume 2*. Sage Publications, London. 2010

[11] Rice P, Ezzy D. (1999). *Qualitative research methods: A health focus.* Oxford University Melbourne, Australia

Appendix 1: Indication of courses and programs currently offered in Australia

Health Informatics Courses	
Institution	Program
Griffith University	Graduate Certificate in Health Informatics
Melbourne University	Bachelor of Biomedicine – Health informatics major
University of Sydney	Master of Information Technology
University of Tasmania	Bachelor of E-Health (Health Informatics (Professional Honours) Graduate Certificate in E-Health (Health informatics) Graduate Diploma in E-Health (Health informatics) Masters of in E-Health (Health informatics)
University of Western Sydney	Graduate Certificate in Health Informatics

University of Wollongong	Master of Health Informatics
University of Queensland	Master of Bioinformatics
Health information management courses incorporating health informatics	
Institution	Program
Curtin University	Bachelor of Health Science (Health Information Management)
La Trobe University	Bachelor of Health Information Management Master of Health Information Management
University of Western Sydney	Bachelor of Information Management and Communications Technology (Health Information Management)
University of Queensland	Master of e-Healthcare
University of Technology, Sydney	Master of Health Services Management
Units	
Institution	Unit
Monash	Nursing Informatics
University of Tasmania	Health Services and Health Informatics
Australian Catholic University	Health Informatics (e-Health)
Short Courses	
Institution	Program
Flinders University	Short Health Informatics Course
University of Western Sydney	Australian Health Informatics Summer School

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

doi:10.3233/978-1-61499-558-6-167

Development and Practice of Store-and-Forward Telehealth Systems in Ophthalmology Dental and Emergency

Di XIAO [a,1], Janardhan VIGNARAJAN [a], Justin BOYLE [a], Ming ZHANG [a], Mohamed R Abdalla ESTAI [b], Marc TENNANT [b], Mei-Ling TAY-KEARNEY [c] and Yogesan KANAGASINGAM [a]
[a] *Australian e-Health Research Centre, CSIRO*
[b] *The University of Western Australia*
[c] *Royal Perth Hospital*

Abstract. Store-and-forward (S&F) telehealth system has been becoming an increasing application in remote medical consultations. In this paper, we will introduce three novel S&F telehealth systems we developed for ophthalmological, dental and emergency applications. We will explain the general system architecture of the S&F systems. Then we will focus on the specific features and components in each system implemented for meeting their respective clinical requirements. In the final section we will present further implementation details and practices and provide discussions.

Keywords. Store-and-forward telehealth, ophthalmology, dental, emergency

Introduction

Store-and-forward (S&F) telehealth refers to the acquisition and storing of clinical information (such as patient demographics, disease symptoms, examination results and other data including images, sounds and videos) and then forwarding the information via computer-based telecommunication methods to another site for clinical consultations or second opinions. A general service model of S&F telehealth is to provide consultations from a specialist using an asynchronous communication to a healthcare provider at a distant clinic, who is directly with a patient seeking medical service. The feedback information from the specialist can include diagnosis, treatment and care management. Based on the information, the healthcare provider can decide the treatment to the patient or make referral/no referral decision.

In the past 15 years, store-and-forward telehealth technology has been becoming a relatively mature activity. S&F telehealth technology has been used in the areas of ophthalmology, otolaryngology, gastroenterology, cardiology, psychiatry [1], dermatology, and neurology, etc. [2]. In Australia, a pilot project, the Skin Emergency Telemedicine Service, was established in Brisbane in 2008 through email referral method for providing diagnostic and management advice from dermatologists to

[1] Corresponding Author: Di Xiao, AEHRC, 65 Brockway Rd, WA 6014, Australia; Email: Di.Xiao@csiro.au.

referring clinicians [3]. In 2009, a pilot project (AUSCARE@) in Queensland (Qld) used telephone, email, videoconference and clinical images and documents by S&F method for diabetic foot ulcer management [4]. Similar S&F teledermatology applications were conducted in the United States, such as four major commercially available systems, Medweb, TeleDerm Solutions, Second Opinion, and Alaska Federal health Care Access Network (AFHCAN). AFHCAN system in Alaska was one of the world's most extensive S&F telehealth systems. According to the statistical data in 2007, from 2001-2007, AFHCAN had provided care to more than 2,7000 patients for the consultations of primary care, otolaryngology, dermatology and others [5] and represented a mature telehealth delivery in ALASKA [6]. In ophthalmological area, several nationwide diabetic retinopathy programs in European countries and the United States by using telemedicine technology have successfully shown the application of S&F model [7], for example, two well-known non-profit S&F telehealth systems serving developing countries are Swinfen Charitable Trust (SCT) [8][9] and Médecins Sans Frontières projects [10].

The practices of the S&F telehealth systems have shown their efficiency in patient referral decision, patient access and even medical education, especially for rural and remote consultations. It also has shown to be more cost-effective compared to synchronous telehealth and in-person models in some clinical areas [11][12]. Despite the S&F telehealth systems reported advantages in patient consultations, the implementation of these systems still face challenges [13]. The security, affordability, efficiency, user-friendliness and compatibility to the existing EMR systems are key issues to be concerned for the practice of S&F systems.

In this paper, we will introduce three S&F telehealth systems we developed and implemented for clinical application in Australia. We will focus on the general system architecture of the S&F systems and specific features and components. We will then present their implementation and practice details.

1. Materials and Methods

Our research team from AEHRC has developed three S&F telehealth systems for clinical application: Tele-ophthalmology system (Remote-I), Communication Tool for Emergency Telehealth Services (CETS), and Tele-dental screening system (Tele-dental).

The Remote-I tele-ophthalmology system was inspired by the idea of providing a simple and easy telemedicine system with any fundus camera to provide screening services for remote and rural healthcare providers in Australia. The Tele-dental screening system is aimed at using smart phone camera and client-server technology to acquire oral images by dental assistants and then send the data to registered dentists for reviewing. This helps the patient-end clinicians to advice the patients on any issues related to their oral health. The CETS aimed at providing efficient information management in emergency telehealth consultations between specialists and remote clinicians.

The three systems have very common features. The diagnosis and consultation requirements are from referring clinicians with limited resources or expertise and the requests are from remote or distant sites. Expert support from specialists for the consultations are necessary. Patient's data from the clinics need to be acquired and stored and then further sent to the specialists for the evaluations and consultations.

1.1. Common Architecture

Figure 1 illustrates the common architecture of the three S&F telehealth platforms. It is a web-based application based on centralised web server. Microsoft Asp.NET server technology is used in server with Microsoft SQL server as the data store. The backend data model has some common components such as: user management, patient demographics, medical history and medications, as well as media data storage. Data transmission is carried over encrypted internet connection through HTTPS protocol. The information is secured through authenticated users and actions are based on user's role in the system. This general architecture also consists a video conferencing component which uses OpenTok conferencing server (www.tokbox.com). The platform also provides efficient notification function to health providers and specialists by embedded email and mobile text messaging systems.

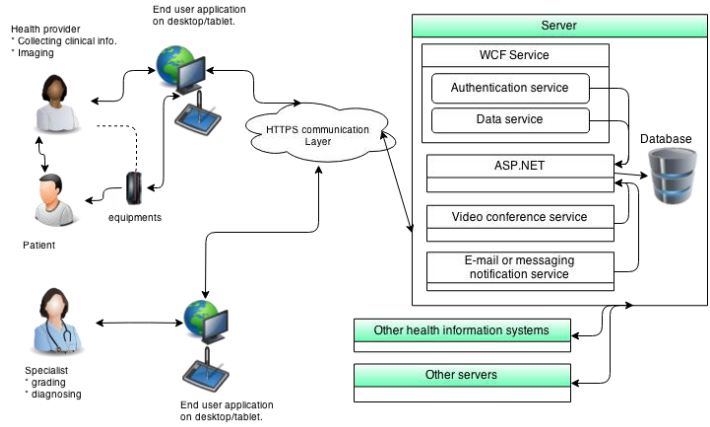

Figure 1. System architecture of the store-and-forward telehealth.

1.2. Implementation for Each Specific System

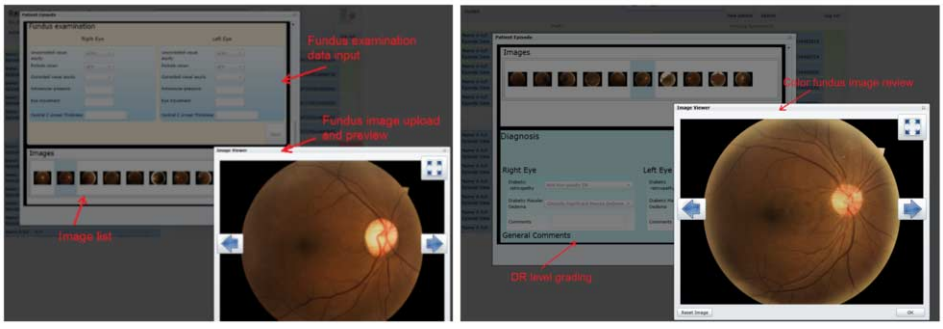

Figure 2. Remote-I tele-ophthalmology GUI (left: clinician web page; right: specialist web page).

Based on the above S&F architecture, Remote-I system for ophthalmology was developed as a web-based application with minimum plug-in installation. Besides computers, the equipment used in clinical site is Optovue DRS retinal camera (non-mydriatic) for capturing patient's fundus photographs. The stored and forwarded data from the patient-end clinicians include patient demographics, diabetes related medical history, eye examinations, current medications and retinal photographs. This information is sent to the specialist (ophthalmologist) and a grading response is sent back with referral/no referral decision. The patient-end clinical staff finalises the treatment plan based on the grading response. Reports can also be generated for the patients. Figure 2 illustrates a data uploading session and a specialist's image grading session.

The Tele-dental screening system combines mobile and web technologies. Android smart phone is used to capture tooth photographs of the patient from different views by our application. The smart phone app's user interface is shown in Figure 3 (left pane). The photographs are sent to a remote dentist via the Tele-dental system and is graded accordingly. The S&F data include patient demographics (limited), photographs of teeth views (e.g. anterior, lateral, lower jaw and upper jaw view) and site specific details (e.g. site name). A registered dentist is notified via an automated email system on any new cases to review. Grading for each tooth will be based on WHO oral health assessment protocol. A grader will review oral images and record "caries or existing restoration" on predefined assessment form through the web-based grading system (Figure 3, right pane). The grading result and potential treatment plan are then read by the patient-end clinician from the web-based system.

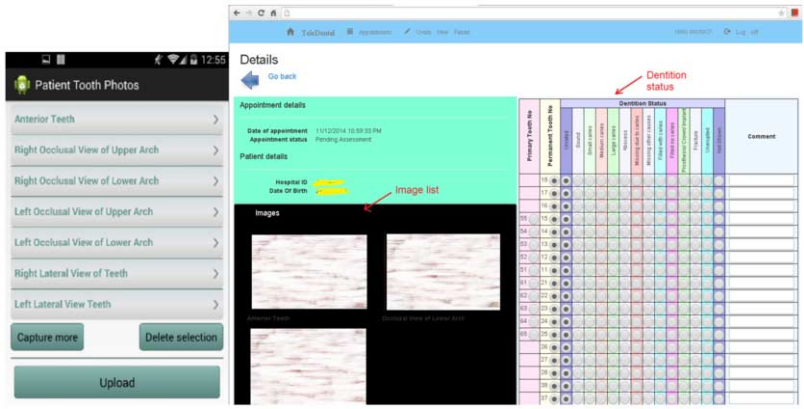

Figure 3. Tele-dental GUI (left: android app for tooth photo capture; right: specialist web page).

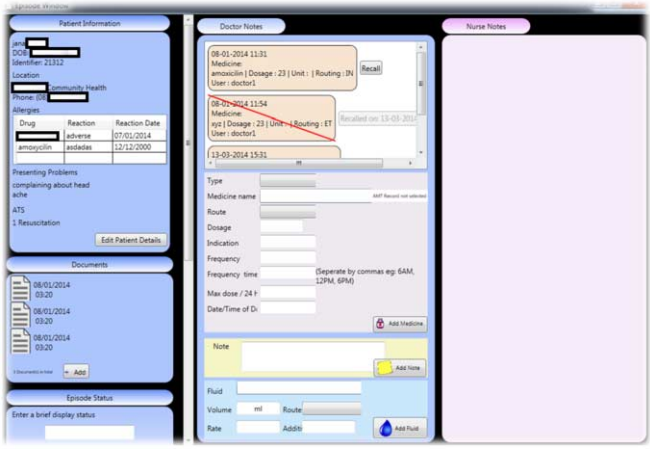

Figure 4. CETS and its GUI.

CETS for emergency telehealth consultations allow interaction between a specialist and a clinician in a real-time tele-emergency consultation. However, it also includes S&F function for asynchronous service in some situations (Figure 4). For the live interaction, the patient's medical condition will also be monitored and stored via the web-based system for record storage and retrieval. The information captured includes patient demographics, allergies, any notes from doctors or nurses, medications and fluids and any documents including images, scanned documents, fax messages. If the users open the current patient's episode on a dashboard, they can see the information relay in real-time. This will then be forwarded to the hospital medical record system based upon the set-up.

2. Practices and Discussions

Remote-I system was used in Broadband enabled Tele-eye care pilot project funded by the Department of Health with the support of our collaborators, WA Country Health Service and the Australian Society of Ophthalmologists through its Indigenous and Remote Eye Health Service (IRIS), Qld Health, WA Health, Department of Communication and NBN Co. The project targeted screening of diabetic retinopathy for rural and remote areas in Australia through telemedicine. An off-line version of the system was added as an extra feature to cater situations with no network access such as mobile van service or network breakdown. During the initial screening, Remote-I system's data design was further modified to suit the preferences of the ophthalmologists and screeners.

From June 2013 to June 2014, the service was delivered to 4 sites (WA's Great Southern and Goldfields regions) in WA and 3 sites (Torres Strait islands) in Qld. Recruiting criteria for the patients were: diabetic over 18 years of age, aboriginal over 30 years of age, over 45 years of age or suffering from a chronic eye condition, were recruited. In total, over 1093 (targeted 900) patients, were screened for eye diseases using Remote-I system. Analysis of diagnosis data indicates 82 cases of DR were

picked up. Critically, 4 patients were diagnosed with proliferative DR and four with severe non-proliferative DR. Diabetic macular edema was noted in 60 patients.

This project reduced the cost of health-care in WA and QLD. For example, it saved 82% (in 288 patients) of the patient travel in Qld, and 95% (in 681 patients) of patient travel in WA during the project period. The project benefited Aboriginal people for eye care. In Qld, 61% of the eye screening examinations were Torres Strait islander/Aboriginal patients, while in WA, 20% were Aboriginal patients. In Qld, 17% of indigenous participants that had DR grading were diagnosed with DR, while in WA, 10% of indigenous participants were diagnosed with DR.

There were minimal training required to allow the users to capture retinal images and upload the data using DRS retinal cameras. The pilot project has shown the increase of the likelihood of early detection of sight-threatening conditions among the remote diabetes patients, especially Aboriginal and Torres Strait Island patients.

Through the pilot project, we have obtained a lot of clinical experience, especially, 1) Screening is more effective if run as part of, and alongside, other services; 2) Because of lack of ophthalmologists and they are busy in clinics, using the ophthalmologists from public health system and assigning a supervisor could make the image grading timely and sustain the service delivery; 3) Implementing software within a client environment should be planned to allow developers to have easy access to the system to fix arising issues; 4) Proper operation of the camera, patient cooperation during the imaging, and the condition of the equipment are important for obtaining images with good quality.

The Tele-dental screening system was a collaborative project between AEHRC and UWA. Now, the system is under trial phase and is being trialed in 3 sites across Australia. In the past 4 months up to 100 patients were screened using the Tele-dental system.

CETS system has completed its prototype design and implementation. We are further revising the CETS system to include further change request and will be trialed out in the near future.

3. Conclusion

In this paper, we introduced three S&F telehealth systems we developed. We presented the common architecture and structure and specific features. The common points in the systems were that we implemented them based on the S&F concept and enabled the data storage with maximum possibility by digital format, which is easy for data transmission and data analysis. We also realised the challenges of implementing the systems, such as the factors of funding, strategic plan, partnership working and technology [13].

References

[1] P.M. Yellowlees, A. Odor, M.B. Parish, A.M. Iosif, K. Haught, and D. Hilty, A feasibility study of the use of asynchronous telepsychiatry for psychiatric consultations, Psychiatr Serv **61** (2010), 838–840.

[2] C. Locatis and M. Ackerman, Three Principles for Determining the Relevancy of Store-and-Forward and Live Interactive Telemedicine: Reinterpreting Two Telemedicine Research Reviews and Other Research, Telemedicine and e-Health **19**(1) (2013), 19-23.

[3] T.M. Biscak, R. Eley, S. Manoharan, M. Sinnott, and H.P. Soyer, Audit of a State-wide store and forward teledermatology service in Australia, Journal of Telemedicine and Telecare **19**(7) (2013), 362–366.
[4] Lazzarini, Lazzarini_2010_Australia_Does the use of store-and-forward telehealth systems improve outcomes for clinicians managing diabetic foot ulcers A pilot study
[5] A.S. Ferguson, J. Kokesh, C. Patricoski, P. hofstetter, and N. Hogge, Impact of store-and-forward telehealth in Alaska: a seven year retrospective. [Online available: http://dhss.alaska.gov/ahcc/Documents/meetings/200908/pdf/AFHCAN_impact.pdf, March 2015]
[6] J. Kokesh, A.S. Ferguson, and C. Patricoski, The Alaska experience using store-and-forward telemedicine for ENT care in Alaska, Otolaryngol Clin North Am. **44**(6) (2011), 1359-74.
[7] Di Xiao, Yogesan Kanagasingam, Chapter 2 Screening of the Retina in Diabetes Patients by Morphological Means, *Teleophthalmology in Preventive Medicine*, Georg Michelson, Springer Berlin Heidelberg New York Dordrecht London, pp. 15-26, 2015.
[8] R. Wootton, K. Youngberry, R. Swinfenw, and P. Swinfenw, Referral patterns in a global store-and-forward telemedicine system, Journal of Telemedicine and Telecare **11**(Suppl. 2) (2005), S2:100–103,.
[9] Verizon Foundation; University of Virginia Health System, Swinfen Charitable Trust and Verizon Foundation Join to Accelerate and Expand Global Telemedicine Program, *Telemedicine Business Week* (2013), 821.
[10] R.d Wootton, J. Liu, and L. Bonnardot, Assessing the quality of teleconsultations in a store-and-forward telemedicine network. Frontiers in Public Health, **2**(8) (2014), 1-8,
[11] T.N. Butler and P. Yellowlees, Cost Analysis of Store-and-Forward Telepsychiatry as a Consultation Model for Primary Care, TELEMEDICINE and e-HEALTH **18**(1) (2012), 74-77.
[12] R. Quade and V. Aulakh, Chapter 15 Economics of screening for diabetic retinopathy using telemedicine in California's safety net, *Digital teleretinal screening*, Springer Heidelberg New York Dordrecht, London. 2012.
[13] V. Joseph, R. M West, D. Shickle, J. Keen, and S. Clamp, Key challenges in the development and implementation of telehealth projects, Journal of Telemedicine and Telecare **17**(2) (2011), 71-77.

This page intentionally left blank

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

Subject Index

Driving Reform: Digital Health is Everyone's Business
A. Georgiou et al. (Eds.)

Author Index

This page intentionally left blank

This page intentionally left blank