Improving Indigenous Patient Education using an Ontology-based ICT Framework

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Introduction

Diabetes is one of the most serious chronic diseases prevalent in the world today. Type 2 Diabetes (T2D) comprises 80% to 90% of all diabetes cases[1]. The first accurate diabetes prevalence study commissioned in Australia led to a 2001 report by the International Diabetes Institute suggesting that almost one in four Australians aged 25 years and older had either diabetes or a condition of impaired glucose metabolism [2]. Diabetes deaths in 2006 were eight times higher in WA's Indigenous people than in non-Indigenous. Diabetes WA reports that in the 2007/08 financial year, 12.37% of all hospitalisations in Western Australia, i.e. 95,775 admissions, involved patients with diabetes, whether as a direct or associated condition [3]. Western Australia has the largest land area (2,532,400sq km) of any Australian State or Territory. Over 72% of Western Australia's population is located in Perth, where principal health care support facilities, medical treatment and pathology testing services are located [4].

Rural and remote communities in WA rely upon thinly-spread, mobility-dependent, over-stretched, ill-equipped and sometimes inaccessible, primary care resources; and on a relatively small cohort of Aboriginal Health Workers of Indigenous ethnicity. These adverse factors are compounded by comparably weak communications infrastructure, and sporadic development of telehealth services [2-3]. Andrew Phillips emphasizes the fact that 'health and its outcomes become worse as remoteness increases' [5]. Remote area Indigenous T2D patients in Western Australia (WA) are disproportionately at risk of developing chronic diseases compared with non-Indigenous people living in or close to urban areas [6].

The Australian 2008 Diabetes Model of Care publication repeatedly references education as a vital and consistent asset in the continuing effort to combat T2D in the Indigenous community [6]. The aim of the T2D patient is to routinely achieve a consistent and safe level of glycemic or 'metabolic' control. Many urban T2D patients self-manage their condition with Point of Care Testing (PoCT) in the home environment. PoCT and related disease management devices offer promise for improving patient health, saving time and expense, and remote monitoring care via ICT, provided that we are able to deliver sustainable and usable connectivity in the needy communities. Connectivity also means the ability to deliver knowledge.

However, self-management through PoCT is not a viable option at this time for Indigenous Australians as inflexible westernized forms of communication have contributed to poor cross-cultural communications and inadequate clinical interactions. A valuable insight to miscommunication in the Australian Aboriginal healthcare dialogue context is illustrated by Cass et al, showing that miscommunication is pervasive, and that trained interpreters provide only a partial solution. A shared understanding of key concepts 'was rarely achieved' and 'miscommunication often went unrecognised'. The frequent phenomena of 'gratuitous concurrence' i.e. the patient answering a yes/no type question by offering a response that the patient thinks the health worker would prefer to hear, was very apparent from this study. One nurse remarked 'I never even considered that they might be saying "yo" (yes) when they are really saying "no". I never even thought of it.' [7].

This paper stems from research into conceptual modelling of an ICT system for management of Type 2 Diabetes Mellitus (T2DM) in rural and remote Aboriginal communities in Western Australia (WA). The solutions proposed here embrace 'telehealth'. Usage of the word in the Australian context falls under the umbrella of the broader e-health applications environment as described by Maeder [8].

The proposition generating this paper however is that education and training of patients and health workers offers great promise for improving health in these communities, both as a precursor and a ubiquitous accompanying feature of the care functions delivered through the ICT-based framework. The learning process is a valuable by-product of the primary aim of facilitating better and more meaningful communication between the patient and medical practitioner; including familiarity and interaction with ICT PoCT devices and communications interfaces. Ultimately the integration of an ontology-supported framework is intended to help Indigenous patients' self-manage type 2 diabetes through improved and culturally appropriate medical consultation dialogue.

Background

A six year study of diabetes primary care services focused on a remote district in northern Australia concluded that investment in quality improvement in primary diabetes care will achieve cost savings through prevention of

hospitalisations[9]. Remote living conditions in extremes of climate common to parts of WA are not always conducive to best results from clinic or home use devices. Becker cautions that accuracy and reliability of testing devices can be affected by environmental conditions [10]. Understanding and operating test instruments properly is a challenge, emphasizing the need for simplicity and proper training.

Australia's National Health and Hospitals Reform (NHHR) commission produced five priorities for improving access and equity to healthcare. This list opens with the statement: Our first priority acknowledges the unacceptable health outcomes of Aboriginal and Torres Strait Islander people. The third priority in the report is directed at 'addressing the problems for people living in remote and rural areas'. The report later states 'our third lever to support an agile, self improving system is the smart use of data, information and communications' [11].

An Australian mixed-method study suggested that telehealth (remote healthcare) remains underused and poorly integrated; and that it places constraints on activities of participants and few actually used it. The study reported a sceptical view of the routine use of telehealth and proposed that success of pilot projects may not indicate long term viability as investment funding and enthusiasm wane with actual implementation[12]. The investment justification process for telehealth projects reflects the complexity of making changes in health care generally and other sources propose caution. While acknowledging telehealth growth in Australia, Michelle Brear found there was limited evidence of clinical benefits resulting from the use of 'telemedicine applications' [13]. The scope of the Brear paper however is a broad surface sweep of a dense and complex subject, as opposed to a specific critique of T2DM telehealth intervention possibilities.

WA telehealth service progress has been limited in part due to extraordinary infrastructure logistics and demographics. The WA Department of Health began a telehealth project in 1999. The project has since expired. A detailed insider perspective of the project is found in the doctoral thesis of Angelita Martini. This study confirmed a consensus among participants about the opportunities for improvements through telecommunications, but the conclusion of her thesis pointed to the 'disjunction between local needs, expectations and interests, and government agendas and policies'. This was accompanied by a call to remodel community health services and change management strategies in support of that objective [14].

In Canada, a vast country with remote extremes where considerable effort has been invested in telehealth development and where a number of Aboriginal e-health initiatives are active, Aboriginal community representatives are seeking greater consultation and e-health systems that are tailored to specific and varied need. Maar et al. state that the emphasis on clinical and academic experts is problematic because 'experts' have 'shallow histories in Aboriginal Communities'. The authors argue that 'research is required on the interplay between Aboriginal cultures and e-health including how the practice of e-health should be adapted to support Aboriginal people's aspirations in health care and self determination in general' [15].

Doctor-patient dialogue inadequacies are receiving much attention from researchers developing ontologies to support health care systems. Barrett has proposed a point-of-service addition to an existing ontology of medical terms for doctor-patient communications, contained as a module in an Arab-English bi-directional machine translation lexicon. This extends beyond those commonly found descriptive symptom and treatment words in the dialogue, making connections using related verb groups such as drink, hurt, inhale [16]. Bailin and Lehmann, emphasizing the issue of bi-directional miscommunication, propose a clinical tool in which an agent-based system could infer the most recent ontologies for clinician and patient [17].

There are many barriers to the successful introduction and long term implementation of ICT-based remote healthcare systems in Western Australia. Firstly, the development of early intervention for diabetes patients via ICT remote monitoring device deployment in rural and remote WA have not been overcome. Projects have generally focused on proving or discounting the remote monitoring investment justification hypothesis. Secondly, an attractive ICT remote monitoring T2DM models for emulation are not readily visible. PoCT device application design research methods are not openly discussed in detail by manufacturers. Thirdly, current healthcare system informatics is clinician-biased, i.e. top-down, provider driven, not patient-centred. Health care service provider communications with patients of a disadvantaged disposition are sociolinguistically limited and therefore clinically inadequate. Lastly, ICT access and usage by and/or for Indigenous people, in remote areas of WA is extremely limited. Currently, there is no significant program, research or plan in evidence for development of appropriate and efficient ICT adoption for T2DM care and education of remote Aboriginal patients.

Methods

The purpose of this proposed framework is to integrate Point of Care Testing (PoCT) into an ICT-based framework that will educate remote indigenous patients on Type 2 Diabetes Mellitus (T2DM) and facilitate better and more meaningful communication between the patient and medical practitioner. The proposed ICT framework will enable the indigenous patient to self manage type 2 diabetes better by providing a culturally

appropriate interface for the patient to interact with the ICT systems and medical practitioners. The component aims within the above primary goal are:

- To develop early intervention education and e-health/telehealth applications using an ICT based framework that will help to counter the extraordinary impact of T2DM on Indigenous (Aboriginal) communities in Western Australia (WA).
- To overcome by design, the known and research-encountered barriers to ICT engagement by Aboriginal people.
- To identify, articulate and assimilate culturally-appropriate informatics, i.e. sociolinguistics, and pragmatics styled interactive human communications, within design parameters for providing better understanding and meaningful communication between the Indigenous patients and the medical practitioners.
- To develop an Australian Aboriginal English Ontology and a T2DM Ontology that will integrate into the developed framework.

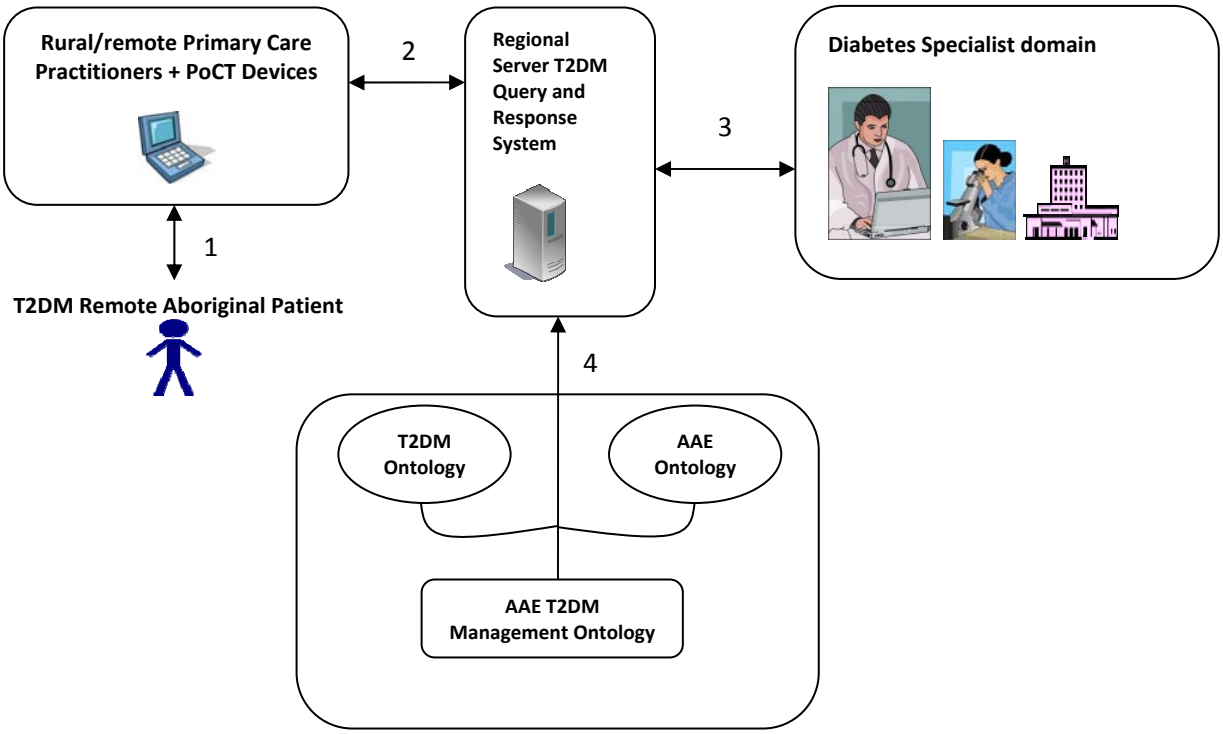

Figure 1: Proposed ICT Framework

While educational value may be inferred within some of the earlier studies, there is generally a deficit of discussion about the high value ancillary educational contribution for patients from diabetes telehealth. Therefore, we are developing a new ICT framework that provides a facility for interface refinement and language localisation for all users to comfortably use the PoCT devices.

Figure 1 is a simple illustration of the primary project ICT framework, showing the interactive links and knowledge exchange streams that over time will feed participants with care related information presented in a manner semantically compatible with education as well as physiological goals.

Evidence Based Design (EBD) methodologies will be applied to determine the environmental application priorities; accordingly the model will be engineered to suit just one type of point of care and monitoring environment. The historical analysis and ethnographic observational analyses methods will be used, intended to help identify the preferred permutation of equipment, software and operating systems, together with the human user communications protocols, that will theoretically provide the foundation as a single conceptual model. Also a combined qualitative and quantitative assessment will annotate focus group discussions and responses to a presentation of conceptual model capabilities and features, involving senior executives of three separate institutional stakeholder groups; and a voluntary participant group of adolescent (High School) Aboriginal students.

Regardless of unpredictable operational factors including PoCT location, integrated device portability or whether interventions are controlled entirely by health workers, the system is intended for eventual self-use by patients; within an unknown timeframe. Moreover, it is assumed from available evidence that the broadband

infrastructure underpinning future telehealth transmission capabilities will be in place and accessible to the relevant stakeholders within the next three to five years (2012-2015).

The significant impact of the proposed framework is as follows:

- **Education of both patients and health care professionals** to achieve ICT supported self-management and timely interventions for T2DM patients close to their local home environment**.**
- **Facilitation of more effective practitioner-patient dialogue**. Prior projects have not provided culture biased ontologies to support care protocols including ICT interface relationships.
- **Reduction of healthcare service viability vulnerabilities.** A Return on Investment (ROI) philosophy is an assumed impact of this research as the concept includes the aim of reducing the cost burden of T2DM on the state healthcare system by reducing hospitalisation and increasing patient self management.
- **Ultimate improvement in the health of and connectivity with disadvantaged Indigenous communities**. The incremental effect of localized and remote monitoring; and point of care intervention has longer term benefits beyond T2DM.
- **Applications and capability growth via enhanced content and device scalability**. It will become feasible to re-engineer for supporting chronic disease populations other than T2DM patients; and for emergency medical response requirements.
- **Potential for shared authorized ICT access to system logs for State and Federal Health productivity evaluations.** Facilitating potential gateway interface for data-feed to future patient Electronic Health Records (EHRs); faster regional and state collation and analysis of T2DM and associated morbidity data; healthcare demand forecasting; and State health care cost–benefit analysis and reporting.

The case study below illustrates the use of our proposed ontology-based ICT framework. Rather than re-invent the wheel, we will enhance existing best practise education tools and PoCT devices by presenting the information in a more meaningful way for the Aboriginal patient, taking into consideration their cultural sensibilities. However, the ontology will also provide an automated translation mechanism so that the healthcare professional can view the information that is relevant to making an expert diagnosis. The use of an ontology is crucial in providing this functionality.

Case Study

Aboriginal patients who are already diagnosed with type 2 diabetes will use a touchscreen display with the assistance of a nurse at a clinic/hospital outpatient facility in remote WA. They will respond to Web-based Australian Aboriginal English (AAE) that incorporates a graphics-audio-video supported questionnaire selected from a menu by the nurse. The patients then use PoCT devices, partly assisted by the nurse to perform diagnostic tests. The PoCT data readings are uploaded, coded for correlation with the individual patient questionnaire answers, for recall by the medical practitioner and patient. The developed ontological layer helps to structure patient practitioner interactions including clinical evaluation along with device readings. Advice, anomalies and other flagged action items are returned to the nurse in clinical terminology, together with a menu. The nurse has the ability to use the menu to display screens to the patient using Australian Aboriginal English and accompanying culturally appropriate modes of communicating advice, formatted for ease of retention sharing and reuse.

We are learning that westernized assumptions about the value of speech and written text are unreliable; such limitations fail to optimize the conversational modalities available when engaging different cultures. This has been demonstrated by the Health Interactive Technology Network (HITNet). HITNet develops and deploys creative media solutions to reduce Indigenous health inequalities. Indigenous adolescents have proved particularly receptive to using new technology with the HITNet health information project in remote Queensland, interacting with multimedia via touchscreen video kiosks. The successful media concepts favour the use of ‘performative’ and participative content in Indigenous communities (as opposed to narrative text) because they are more attuned to listening and watching versus literacy-based media [18-19].

Conclusions

We believe that understanding and meaningful communication between the Indigenous patients and the medical practitioners will be greatly enriched by the merging and support of an Australian Aboriginal English Ontology with a T2DM Ontology integrated into the developed semantically interoperable framework. This represents a first step toward educating patients and practitioners in diabetes management in the unique circumstance of the rural and remote environment.

Future work will be on the T2DM prevention and management role of the system, recognizing the high value of nutrition and exercise knowledge, habits and practices. This however represents new challenges, as dietary considerations are complex, closely related to the finer characteristics of individual patient uniqueness, i.e. ethnicity, the home environment and multiple disadvantages too commonly determined by social status.

References

[1] (ND, 22 July 2009). *Chronic Diseases*. Available: http://www.who.int/topics/chronic_diseases/en/

[2] "The Australian Diabetes, Obesity and Lifestyle Study 'Diabesity & Associated Disorders in Australia – 2000 The Accelerating Epidemic'" International Diabetes Institute, Canberra, 2001.

[3] "Diabetes in Western Australia," Diabetes WA and Epidemiology Branch, Department of Health, Western Australia, Ed., ed. Perth, 2009.

[4] (2009, *1306.5 - Western Australia at a Glance*. Available: http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/BDA0B5E729A7E3C7CA25758A000E1DC4/$File/13065.pdf

[5] A. Phillips, " Health status differentials across rural and remote Australia " *Australian Journal of Rural Health* vol. 17, no. 1, pp. 2-9, 2009.

[6] "Diabetes Model of Care," Department of Health Western Australia, Endocrine Health Network Ed., ed. Perth, 2008.

[7] A. Cass, *et al.*, "Sharing the true stories: improving communication between Aboriginal patients and healthcare workers.," *Medical Journal of Australia* vol. 176, no. 10, pp. 466-70., 2002.

[8] A. Maeder, "e-Research Meets e-Health," presented at the Australasian Workshop on Health Data and Knowledge Management (HDKM 2008) Conferences in Research and Practice in Information Technology (CRPIT), Wollongong, NSW, Australia, 2008.

[9] R.McDermott and L.Seagal, "Cost Impact of Improved Primary Level Diabetes Care in Remote Australian Indigenous Communities," *The Australian Journal of Primary Health*, vol. 12, no. 2, 2006.

[10] G. Becker, *Type 2 diabetes An Essential Guide for the Newly Diagnosed*. Philadelphia, PA USA: Da Capo Press Perseus Books 2007.

[11] C.Klersy, A.De Silvestri, G. Gabutti, F. Regoli and A. Auricchio, "A Meta-Analysis of Remote Monitoring of Heart Failure Patients," *Journal of American College of Cardiology*, vol. 54 no. 18, 2009.

[12] E. Mauldon, "The Use of and Attitudes Towards Telehealth in Rural Communities " *Australian Journal of Primary Health* vol. 13, no. 3, 2007

[13] M. Brear, "Evaluating telemedicine: lessons and challenges," *Health Information Management Journal* vol. 35, no. 2, 2006.

[14] A. Martini, "Community Participation In Government And Private Sector Planning: A Case Study Of Health And Telecommunications Planning For Rural And Remote Western Australia," School of Nursing, Division of Health Sciences Murdoch, Perth, 2006.

[15] M. Maar, A. Seymour, B. Sanderson and L. Boesch, "Reaching agreement for an Aboriginal e-health research agenda: the Aboriginal telehealth knowledge circle consensus method," *Rural and Remote Health (The International Journal of Rural and Remote Health Research, Education Practice and Policy)*, vol. 10, no. 1299, 2010.

[16] L. Barrett, "Designing an Ontology of Dialogue Elements Modeling Doctor-Patient Exchanges" in *LREC 2006 Workshop on Acquiring and Representing Multilingual, Specialized Lexicons: the Case of Biomedicine*, Genova, Italy, 2006.

[17] S. C. Bailin and H. B. Lehmann, "Facilitating Physician-Patient Dialogue through Ontology Negotiation," in *16th IEEE Symposium on Computer-Based Medical Systems (CBMS'03)*, 2003, p. pp 248.

[18] H.Travers, E.Hunter, J.Gibson and J.Campion. (2007, 23 October 2009). *Pride and performance: Innovative multimedia in the services of behavioural health change in remote Indigenous settings.* Available: http://www.hitnet.com.au/docs/VSMM%20Paper%20Sept07.pdf

[19] E.Hunter, *et al.*, "Pride and performance: evaluation challenges of a multimedia and information technologies project in remote Aboriginal Australia. ," *Australasian Psychiatry*, vol. 17, no. 1, pp. S155-158, 2009.