

# Coupling of Indigenous-patient-friendly cultural communications with Clinical Care Guidelines for Type 2 Diabetes Mellitus

David Forbes, Amandeep Sidhu and Jaipal Singh

Digital Ecosystem and Business Intelligence Institute  
Curtin University  
Perth, Australia

david.e.forbes@postgrad.curtin.edu.au, {a.sidhu, j.singh}@curtin.edu.au

## Abstract

Distance, terrain, climate and inadequate medical resources seriously constrain health care accessibility for rural and remote Indigenous communities of Western Australia (WA). Management of the Type 2 Diabetes Mellitus (T2DM), a chronic condition affecting Indigenous people much more than non-Indigenous, requires a complex assortment of time-sensitive communications activity and interventions to avert serious complications. Communications barriers arising from pervasive cultural misunderstanding in primary care go far beyond language differences and routine translation techniques. Practitioners and patients lacking the ability to share understanding in the examination and testing discourse need a culturally sensitive purpose-driven informatics system of support for the Patient-Practitioner Interview Encounter (PPIE). The dominant unidirectional clinician-biased forms of communication employed by healthcare professionals are a major barrier. Our developing communications support model utilizes the mapping of ontologies. The Community Healthcare ontology is dedicated to mapping a clinical taxonomy for T2DM national guidelines to Aboriginal English (AE). The eventual user interface will represent Aboriginal patient-culture use of interactive audio visual media in the primary healthcare setting. This research objective establishes respect for the Aboriginal patient's dialectal and pragmatic preferences, enabling us to couple these preferences with Australia's Standard English clinical communications practice for treatment and care of Indigenous T2DM patients. A critical capability of the eventual application, especially when phrase ontology guidance enters the interface will be the interception of ambiguities and mitigation of misinterpretation risk. The emphasis is concentrated on bi-directional communications assistance that will not only enhance the Aboriginal patient opportunity to contribute to the PPIE, but will reinforce the value of and reciprocal respect for, sound clinical practice.

*Keywords: Indigenous Health, Health Communication, Aboriginal English Ontology, Patient-Practitioner Interview Encounter, Type 2 Diabetes*

## 1 Introduction

The complexities, volume and time consumption factors of primary care patient evaluation processes are presenting healthcare practitioners globally with extraordinary decision-making demands (Barlow, 2009, Fiscella and Epstein, 2008). Access to healthcare information via the Web is ubiquitous for many people in developed countries; and interpretation by non-medically-trained patients can potentially help or hinder patient-practitioner interactions (Seckin, 2010). We suggest that this is further contributing to healthcare inequities affecting patients who are socio-culturally disadvantaged, as advancements in healthcare literacy are increasingly influenced by self-education driven by access to and affordability of, Information Communications Technologies (ICT). In the primary healthcare setting, complexity includes volume, time-sensitive analysis and choice of treatment and care options, heavily influenced by clinician service-time constraints. This presents a strong case for actively seeking cost efficient smart two-way interview support systems, introducing ICT models that will enrich the disadvantaged patient communications capabilities while alleviating the risk of clinician task overload and burn out. In this work we are focused on patient-provider interaction involving Western Australia Aboriginal Type 2 diabetes patients, particularly those who are additionally disadvantaged by the healthcare service delivery constraints of rural and remote areas within this large, demographically unbalanced, logistically challenged state.

## 2 Background

WA's remote area Indigenous T2DM patients are disproportionately at risk of developing chronic diseases compared with non-Indigenous people living in or close to urban areas (ENDOCRINE HEALTH NETWORK, 2008). Western Australia has the largest land area (2,532,400sq km) of any Australian State or Territory. Its coastline of 12,500km amounts to 34% of Australia's total coastline. 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.

Diabetes is one of the most serious chronic diseases prevalent in the world today. The World Health Organization (WHO 2009) describes chronic diseases as 'diseases of long duration and generally slow progression'. Type 2 Diabetes Mellitus (T2DM) comprises 80% to 90% of all diabetes cases (WHO 2009). 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 (International Diabetes Institute, 2001).

2009 statistical data (ABS 2010, HealthInfoNet 2010) show the high incidence of diabetes in the Indigenous population compared with non Indigenous.

- (a) Proportions of people reporting diabetes/high sugar levels with Indigenous to non-Indigenous ratios, Australia, for the year 2004-2005, indicate that 1% of Indigenous people aged between 15-24 have diabetes, versus 0.5% of non-Indigenous population of the same age, a ratio of 2.
- (b) In the age group 25-34 the (2004-05) percentages were 4.3% Indigenous, 0.6% non-Indigenous, a ratio of 7.2
- (c) In the age group 55 years+ the percentage of the Indigenous population with diabetes (2004-05) was 32.1% compared with 11.2% of the non-Indigenous population, a ratio of 2.8

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 (DIABETES WA, 2009).

Rural and remote communities 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 (M.Cribbs and K.Glaister, 2007, P.Van Ast and A.Larson, 2007)

For urban, rural and remote region T2DM patients, the common initial evaluation locus is the primary care environment. Convenient and timely access to a General Practitioner (GP) and referral to specialist support diminishes with remoteness, with extreme contrast in levels of service and capabilities experienced by remote patients compared with their urban counterparts. Within the innumerable coordinates of T2DM and co-morbidity management for Indigenous patients, primary care communications occupies a key quality status for reliable evaluation of care priorities. There is evidence to show that patient-practitioner interactions are falling short due to a cultural disconnect leading to misunderstandings between clinicians and their Aboriginal patients (Carrillo et al., 1999, Kagawa-Singer and Kassim-Lakha, 2003, Shahid et al., 2009, Lawrence et al., 2009).

We have concluded from this research that for a variety of reasons applicable to both Indigenous and non-Indigenous chronic disease patients, the dominant unidirectional clinician-biased forms of communication employed by healthcare professionals are a major barrier to communications and thereby contribute to lower efficacy in patient evaluation and care outcomes. Modelling for elevation of patient communication

capabilities, potentially a bi-directional and constructive patient empowerment augmentation of existing clinical care is an attractive route to counter this.

Specifically in the context of Aboriginal patient communication, there is an intricate montage of socio-cultural nuance that is not widely understood, and therefore not appropriately valued and respected, by a sizeable percentage of WA's healthcare providers. Language translation and the use of interpreters, while having some worth, are limited in both availability and value. Literal translation in isolation contains risk characteristics that may exacerbate misunderstanding (Trudgen, 2000). The healthcare sector also has its own specialist culture to add further distance to differences in participant ethnicity and socio-economic background. The cultural disconnect(s) can lead to inadequate information exchange, zero information exchange, potential but unqualifiable relevance/irrelevance in the exchange, misinformation, misinterpretation, and misunderstanding during patient-practitioner encounters (Trudgen, 2000). This emphasizes the need to recognize that technology must go beyond technical capability to promote and augment productive PPIE relationships. The communications deficit for Indigenous peoples globally is apparent in disease treatment and care protocols other than T2DM. Reporting on patients' views about effective communications Shahid et.al highlights treatment disparities affecting Aboriginal cancer patients in Western Australia hospital settings (Shahid et al., 2009). ICT is viewed by other researchers as a means to help overcome these disparities through communications enhancement. Automation prospects include the use of medical dialogue management systems (Beveridge and Fox, 2006); and multi-layered conversational intelligent agent systems (Goh et al., 2007). In the absence of such developments specific to Australian Aboriginal PPIE support, we have embarked upon the design of a system that establishes value of and respect for the Aboriginal patient's dialectal and pragmatic preferences, thereby enabling us to couple these preferences with Australia's Standard English clinical communications practice in the treatment and care of Indigenous T2DM patients.

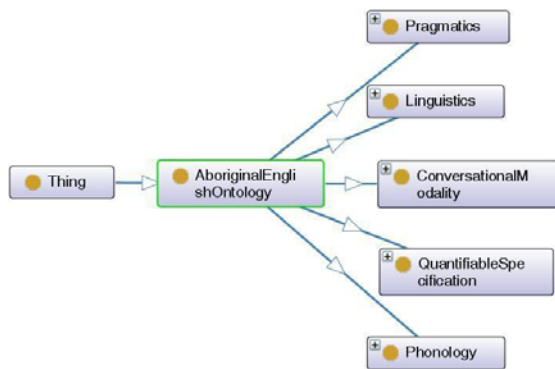
### 3 Methodology

Our developing model utilizes the mapping of ontologies. A Community Healthcare ontology is dedicated to mapping a clinical taxonomy for T2DM national guidelines (DIABETES AUSTRALIA, 2009) to Aboriginal English (AE) ontology. The knowledge representation outcome will be achieved through formal semantics and syntax applications using the Web Ontology Language (OWL).

AE is a dialectal form of communication that with some individual word variation is used within Australian Aboriginal communities nationwide where Standard Australian English has become the dominant local language of society's establishment, i.e. schools, clinics, hospitals. Most commonly it represents the uniquely Aboriginal conversational modality that takes place in the family home, and is often cross-referred as 'home talk'. Harnessing AE in readiness for two-way mapping with Standard English T2DM guideline terminology through

ontology development requires validation by AE speakers from within Aboriginal communities. This process will be conducted and managed by Aboriginal focus groups. The eventual user interface is not discussed here, save to say that it will represent Aboriginal patient-culture-driven access to and use of interactive audio visual media to correlate and merge digitally generated assessment test data with information that reflects the bi-directional PPIE. Systems that induce a mutually cooperative PPIE are likely to favour Aboriginal-friendly environment designed touch screen facilities. There is evidence to show that Aboriginal communities willingly embrace and culturally adapt their usage of touchscreen technology to their ultimate advantage (Auld, 2002).

The AE ontology tree at Figure 1 illustrates the ontology scope as at this writing. This conveys the considerable range of AE communications structure and pragmatics, with some latitude for expansion still remaining. For example, instances of subclass properties under *Pragmatics* and also under *Conversational Modality* may include PPIE Phrases, divided into *AE Speaker Sent* and *AE Speaker Received* modes.

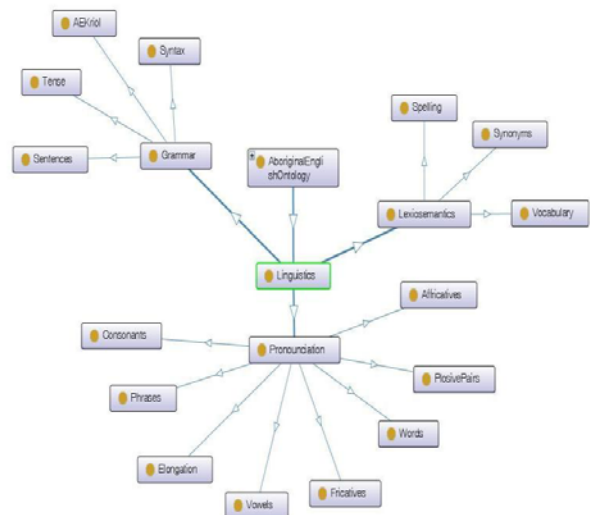


**Figure 1: Aboriginal English Ontology**

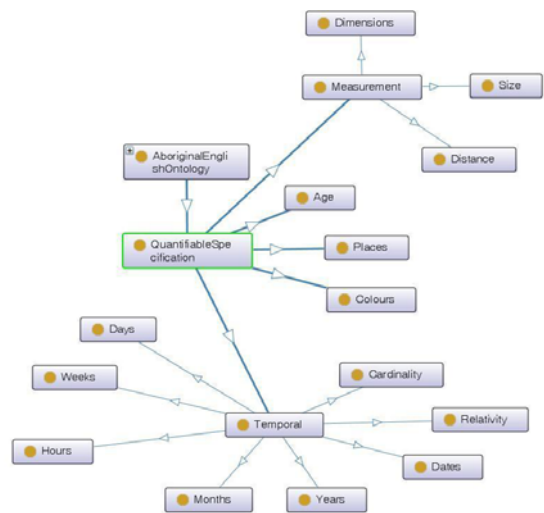
A critical capability of the eventual application, especially when phrase ontology guidance enters the interface will be the interception of ambiguities and mitigation of misinterpretation risk. The work discussed here dwells on this aspect. In AE the risk of ambiguity and misunderstanding is pervasive. For example research has shown that gratuitous concurrence, or more plainly put, the inclination of many Aboriginal patients to agree automatically with their clinicians without concern for accuracy, is a common practice which can seriously devalue the treatment and care plan outcome of the PPIE. This is a product of weak cross-cultural communications, sometimes arising due to the ‘power distance’ between patient and clinician. As we build the ontologies we are breaking down and analysing the most distinct differences between AE and SE discourse. In this process we are identifying the interplay requirements of the semantic and syntactic layers and ontology filters that will effectively intercept enquiry and response content and propose alternate meanings of questions asked and information offered in both directions during or in support of the PPIE.

Semantics and syntax deliberations may occur within or in consequence of many different facets of ontologies supporting AE-centred PPIE. At Figure 2 is the Linguistics parent class, with the ‘*Lexicosemantics*’

(Lexicon Semantics) subclass and *Synonyms* properties; and at Figure 3 is the ‘*QuantificationSpecification*’ parent class with a number of subclasses and different properties that describe how the Aboriginal world view quantifies and qualifies such things as Temporal which references time and its relationship with events; and Measurement which also expresses distance, dimensions and size in relational terms.



**Figure 2: Aboriginal English linguistics**



**Figure 3: Quantifiable specification**

These characteristics do not align comfortably or translate easily with Standard English forms of explanation or questions about quantity. In particular chrono-linear descriptions familiar to westernized clinicians have little meaning in a culture for which there is no beginning and no end.

Table 1 is a sampling illustration of the nature of the proposed PPIE arena, explained in Standard English. The table represents preparatory work for pragmatic contextual translation to AE comprising (a) selected data from Diabetes Management in General Practice Guidelines for Type 2 Diabetes 2009/10 (DIABETES AUSTRALIA, 2009); and (b) research-based commentary and guidance on ambiguity, misinterpretation and issues (Lowell, 1998). The latter is found in AE educational

literature (Malcolm et al., 1999) and will be expanded from the work of the Aboriginal focus groups.

Sample heading T2DM Clinical Guidelines (RACGP /Diabetes Australia)	Preparatory advice/commentary for conversion (code-switching) to AE ontology supported PPIE
Note: General Form of patient interaction is Standard Australian English conversational and written text, minimal diagrams	<ul style="list-style-type: none"> <li>Aboriginal English (AE) PPIE will use little to no formal/technical words</li> <li>will significantly reduce written text</li> <li>interface will optimize artwork/diagrams, audio-visual media</li> </ul>
Initial assessment Note: Westernized clinical assessment lacks cultural empathy.	<ul style="list-style-type: none"> <li>Use empathetic AE expressions to secure trust.</li> <li>Direct and multiple choice questions are inappropriate and commonly ineffectual.</li> <li>Adapt to 'Yarning' interactive mode.</li> <li>Anticipate gratuitous concurrence.</li> <li>Establish patient-preferred quantifying.</li> <li>Use AE ontology PPIE system</li> </ul>
Plan of continuing care Note: Westernized assumptions unsafe. Patients may overtly or covertly prefer ignorance of their condition.	<ul style="list-style-type: none"> <li>AE Two-Way to assess disadvantaged circumstances, home carer environment</li> </ul>
Referral :Expect anxiety, reluctance to travel	<ul style="list-style-type: none"> <li>Anticipate need to explain in basic words what the referral means.</li> </ul>
Counselling the person with diabetes (includes Initial management; Nutrition; Physical activity)	<ul style="list-style-type: none"> <li>Aboriginal Nurse or other Aboriginal Health Worker (AHW) presence/ contribution important.</li> <li>Use AE PPIE, avoid posing question: "Do you understand?"</li> </ul>
Self-monitoring; Medical monitoring; quarterly & annual reviews. Extreme care with terminology.	Explanations for the patient are important. AE PPIE will simplify by avoiding long medical terms.
Medication + Problems with medications.	<ul style="list-style-type: none"> <li>Identify/ intercept/remedy gratuitous concurrence and non-adherence to recommended medication routines.</li> <li>AE PPIE uses simplified dosage advice including side-effects, consequences of non-compliance.</li> </ul>
Oral hypoglycaemic agents Insulin treatment; Insulin delivery; Insulins available	<ul style="list-style-type: none"> <li>As above.</li> <li>Correlate with pathology.</li> <li>AE PPIE to explain 'what' 'how' and 'why'.</li> </ul>
Hyperglycaemic emergencies; Diabetic ketoacidosis; Hyperosmolar non-ketotic coma; Factors complicating management	<ul style="list-style-type: none"> <li>Use AE PPIE system to explain.</li> <li>Facilitate sharing clinically preferred response actions with carers/family.</li> </ul>
Macrovascular disease; Hypertension; Dyslipidaemia; Renal damage; Eye damage; Foot problems; Neuropathy	<ul style="list-style-type: none"> <li>Use AE PPIE system to simplify explanation.</li> <li>facilitate sharing implications with carers and family.</li> <li>Anticipate misunderstanding phrases in AE PPIE yarning formats to intercept/remedy.</li> </ul>
Diabetes and reproductive health; Pregnancy Gestational diabetes	<ul style="list-style-type: none"> <li>Consult with Aboriginal Nurse or Aboriginal Health Worker for bi-directional accuracy</li> <li>Anticipate gender sensitivities</li> </ul>

**Table 1: Sampling of T2DM guideline processes for preparatory mapping to AE ontology**

#### 4 Evaluation

The Aboriginal focus group engagements will extend to a series of reviews of the core and stem content of the phraseology emanating from the earlier of the research and focus group findings. This will seek to test and establish reliability of both commonly used every day speech with cultural grammatical constructs; and circumstance-driven embedding of clinical language AE equivalents. Efficacy of the ontological framework will also be tested refined and enabled through scrutiny by and advice from primary care General Practitioners and clinical health expertise available through ongoing academic supervision. Review findings will be examined for pertinence to the applications and interface concepts, and options will be considered where it proves necessary to orientate the intended outcome through ontology changes. In this event, significant (versus marginal) change will be revisited for evaluation by the sources described above. In the context of interface acceptance, e.g. style and ergonomic factors, examples of touch screen and surface computing models will be displayed for viewing and discussion in the latter focus group sessions.

Our work has accordingly taken us toward development of a system whereby ICT will offer intelligent support for communications regardless of location in what we term the Patient-Practitioner

Interview Encounter (PPIE). We recognize that perception of 'patient empowerment' may unintentionally suggest a severe shift away from established and reliable T2DM clinical assessment and care management. The emphasis however is concentrated on bi-directional communications assistance that will not only enhance the Aboriginal patient opportunity to contribute to the PPIE, but will reinforce the value of and reciprocal respect for, sound clinical practice. For this we rely upon accredited Australian T2DM guideline sources, notably from the Royal Australian College of General Practitioners and Diabetes Australia. This is further supported by accredited sources of Diabetes Education and Aboriginal Nurse Training, as well as WA state government education specialists in Aboriginal literacy.

#### 5 References

- INTERNATIONAL DIABETES INSTITUTE. 2001. The Australian Diabetes, Obesity and Lifestyle Study 'Diabesity & Associated Disorders in Australia – 2000 The Accelerating Epidemic' International Diabetes Institute, Canberra
- ENDOCRINE HEALTH NETWORK. 2008. Diabetes Model of Care. In: DEPARTMENT OF HEALTH WESTERN AUSTRALIA, ENDOCRINE HEALTH NETWORK (ed.). Perth.
- DIABETES WA. 2009. Diabetes in Western Australia. In: DIABETES WA AND EPIDEMIOLOGY BRANCH, DEPARTMENT OF HEALTH, WESTERN AUSTRALIA (ed.). Perth.
- DIABETES AUSTRALIA. 2009. Diabetes Management in General Practice - Guidelines for Type 2 Diabetes. Diabetes Australia and The Royal Australian College of General Practitioners.
- ABS. 2010. 4704.0 - The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, 2010 [Online]. Australian Bureau of Statistics. Available: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/lookup/4704.0Chapter3002010> [Accessed 27 July 2010].
- HealthInfoNet. 2010. Summary of Australian Indigenous health, 2009 [Online]. Mount Lawley WA: Australian Indigenous HealthInfoNet Available: <http://www.healthinfonet.ecu.edu.au/health-facts/summary> [Accessed 27 July 2010].
- WHO. 2009. Chronic Diseases [Online]. World Health Organization. Available: [http://www.who.int/topics/chronic\\_diseases/en/](http://www.who.int/topics/chronic_diseases/en/) [Accessed 22 July 2009].
- AULD, G. 2002. What Can We Say about 112,000 Taps on a Ndjebbana Touch Screen? *The Australian Journal of indigenous Education* 30 1-7.
- BARLOW, J. 2009. Creating a Universal Medical Language for WHO Mayo Clinic. *Discovery's Edge*. Online: Mayo Clinic.
- BEVERIDGE, M. & FOX, J. 2006. Automatic generation of spoken dialogue from medical plans and

- ontologies. *Journal of Biomedical Informatics*, 39, 482-489.
- CARRILLO, J. E., GREEN, A. R. & BETANCOURT, J. R. 1999. Cross-Cultural Primary Care: A Patient-Based Approach. *Ann Intern Med.* , 130, 829-834.
- FISCELLA, K. & EPSTEIN, R. M. 2008. So Much to Do, So Little Time: Care for the Socially Disadvantaged and the 15-Minute Visit. *Arch Intern Med*, 168, 1843-1852.
- GOH, O. S., DEPICKERE, A., FUNG, C. C. & WONG, K. W. 2007. A Multilevel Natural Language Query Approach for Conversational Agent Systems. *IAENG International Journal of Computer Science*, 33.
- KAGAWA-SINGER, M. & KASSIM-LAKHA, S. 2003. A strategy to reduce cross-cultural miscommunication and increase the likelihood of improving health outcomes. *Acad Med.* 78(6), 78, 577-87.
- LAWRENCE, M., DODD, Z., MOHOR, S., DUNN, S., CRESPIGNY, C. D., POWER, C. & MACKEAN, L. 2009. Improving the Patient Journey: Achieving Positive Outcomes for Remote Aboriginal Cardiac Patients. Cooperative Research Centre for Aboriginal Health, 2009
- LOWELL, A. 1998. Cultural Knowledge in Aboriginal Health Care. A review of two subprograms of the Cooperative Research Centre for Aboriginal and Tropical Health's Indigenous Health and Education Research program Available: [http://www.crcah.org.au/publications/downloads/Communication\\_and\\_Cultural.pdf](http://www.crcah.org.au/publications/downloads/Communication_and_Cultural.pdf) [Accessed 12 November 2009].
- M.CRIBBS & K.GLAISTER 2007. 'It's not easy': Caring for Aboriginal clients with diabetes in remote Australia. *Contemporary Nurse* 25 163-172.
- MALCOLM, I. G., HAIG, Y., KÖNIGSBERG, P., ROCHECOUSTE, J., COLLARD, G., HILL, A. & CAHILL, R. 1999. *Two-Way English: Towards More User-Friendly Education for Speakers of Aboriginal English.*, Mount Lawley, Centre for Applied Language and Literacy Research, Edith Cowan University and Education Department of W.A.
- P.VAN AST & A.LARSON 2007. Supporting Rural Carers Through Telehealth. *Rural and Remote Health (The International Journal of Rural and Remote Health Research, Education Practice and Policy)* 7:623
- SECKIN, G. 2010. Cyber patients surfing the medical web: Computer-mediated medical knowledge and perceived benefits. *Comput. Hum. Behav.*, 26, 1694-1700.
- SHAHID, S., FINN, L. D. & THOMPSON, S. C. 2009. Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting. *The Medical Journal of Australia*, 190 574-579.
- TRUDGEN, R. 2000. *Why Warriors Lie Down and Die*, Parap, NT, Aboriginal Resource and Development Services Inc.