

## Posters

# A complete diabetes patient profile for consumer partnership in care

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## Profile for patient information needs

Self-management education is a particular cornerstone of successful diabetes management – the patient must become an active and informed partner in his/her own care to achieve success. There are many sources, both printed and web-based, for consumer-oriented diabetes information; however, the information needs of individual diabetic patients vary widely. Thus, there is exciting potential for tailoring online information presentation to the individual patient. In fact, systems to provide tailored diabetes education have been developed.<sup>1,2</sup> However, these systems focus on the clinical aspects alone and fail to consider the complete model of the diabetic patient as a user.

We see three components as essential to a patient information needs (PIN) profile for providing diabetic patients with the right information at the right time.

- 1 Clinical profile: Scheitel *et al.* suggest that patients' problem lists should be provided by physicians rather than by patients since their study shows that patients failed to report 68% of all health problems and 54% of the most important health problems diagnosed by the physician.<sup>3</sup> Hence, patients' disease-related data should be obtained from their medical records rather than from the patients themselves.
- 2 Demographic/psychosocial/knowledge profile: Delamater *et al.* suggest that psychosocial factors play an integral role in the management of diabetes in both children and adults and psychosocial therapies

can improve regimen adherence, glycaemic control, psychosocial functioning and quality of life.<sup>4</sup> We need to provide appropriate information – there is no sense counselling a vegetarian on the advantages of lean meat, or describing exercise routines that are beyond a patient's abilities. Ongoing knowledge assessment should dictate the level of information presentation.

- 3 Phase of coping: Hernandez suggests a three-phase model of patient development in coping with diabetes spanning an initial phase of fragmented understanding, a 'turning point', and ultimate 'science of one' wherein the patient develops a matured personal approach.<sup>5</sup> The web is full of information aimed at broad overviews appropriate to the initial stage, but appropriate information support for later stages is quite different (and harder to find).

## Method and prototype

We are developing a patient diabetes education system based on our philosophy of a complete patient profile in concert with patient focus groups, physicians and nurse educators at The Queen Elizabeth Hospital Diabetes Centre in metropolitan Adelaide, South Australia. On the surface, the system does not appear markedly different from other web content (see Figure 1), however, we maintain a patient profile with particular emphasis on the patient's ongoing knowledge deficits apropos to their condition (knowledge push) and information interests/needs that aid



(a)

(b)

**Figure 1** Diabetes self-management information from Sharon: (a) main screen; (b) foot care subsection accessed from patient-specific issue list (top right) or by clicking the body outline's foot

formulation of a knowledge-seeking agenda (knowledge pull, manifest as a visible question list).

## REFERENCES

- 1 Miksch S, Cheng K and Hayes-Roth B (1996) The patient advocate: a cooperative agent to support patient-centered needs and demands. *Proceedings of the AMIA Annual Fall Symposium (formerly SCAMC)*. AMIA: Washington, DC.
- 2 McRoy S, Liu-Perez A and Ali S (1998) Interactive computerized health care education. *Journal of the American Medical Informatics Association* 5 (4): 347–56.
- 3 Scheitel S, Boland B, Wollan P and Silverstein M (1996) Patient–physician agreement about medical diagnoses and cardiovascular risk factors in the ambulatory general medical examination. *Mayo Clinic Proceedings* 71 (12): 1209–10.
- 4 Delamater A, Jacobson M, Anderson B et al. (2001) Psychosocial therapies in diabetes: report of the psychosocial therapies working group. *Diabetes Care* 24: 1286–92.
- 5 Hernandez C (1996) Integration: the experience of living with insulin dependent (type 1) diabetes mellitus. *Canadian Journal of Nursing Research* 28 (4): 37–56.

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Accepted July 2002