

Virtual community consultation? Using the literature and weblogs to link community perspectives and health technology assessment

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Abstract

Background Community views, expressed in social impact assessments and collected through community consultation, should play an important role in health technology assessment (HTA). Yet HTA methodologists have been slow to include outcomes of these forms of inquiry in analyses, in part because collecting community views is time-consuming and resource intensive.

Objective To explore how community views sourced from published studies, grey literature and informal internet web pages can inform HTA.

Methods A technology reviewed by Adelaide HTA in 2004 was selected: retinal photography for detection of diabetic retinopathy. Published literature, 'grey' literature and informal web pages were searched to examine the availability of evidence about service community and user community views with respect to this technology. Particular efforts were made to source evidence relating to rural, remote and Aboriginal populations.

Results We found that journal articles, reports from the grey literature and informal internet web pages (including blogs and discussion forums) can provide valuable insight into community views. Although there was little empirical evidence relating to the experience of diabetes and diabetes management in rural, remote and Aboriginal communities, there were indications that some evidence may be transferable from other populations.

Conclusions Community perspectives on selected health technologies can be gauged from available resources in published and grey literature and perspectives collected in this way can provide insight into whether the introduction of the technology would be acceptable to the community. The limitations of this approach are discussed.

Introduction

Health technology assessment (HTA) is a multi-disciplinary field that studies the medical, social, ethical and economic implications of the development, diffusion and use of health technology. HTA is increasingly used as a tool for making difficult decisions with respect to funding for new medical interventions within the context of limited resources. It has moved from a focus on the technical efficacy of specific health technologies to the use of HTA in decision-making with respect to the provision of services.¹ Community perspectives are important in this complex area for a number of reasons: to evaluate the acceptability, social impact and potential uptake of a technology; to expand our understanding of the ethical significance of an intervention (including unintended consequences); and for political reasons.²

There are a number of ways in which community perspectives on health technologies can be accessed. Focus groups, stakeholder interviews, population surveys and public town meetings can all provide important and valuable information. However, collection of community perspectives using empirical research is expensive and time consuming, particularly, where affected communities live in rural and remote areas. Therefore, we asked the question: can we create a 'virtual community consultation' using the literature and websites to collect community views on selected health technologies?

To examine this question we used a case study: a rapid review entitled 'Detection of diabetic retinopathy utilizing retinal photography in rural and remote areas' carried out in October 2004 by the Adelaide Health Technology

Assessment (AHTA)³ hereafter called 'AHTA rapid review'. Diabetic retinopathy is a complication of long-term diabetes related to high blood glucose levels and/or elevated blood pressure which causes vision loss and ultimately may cause blindness. The AHTA rapid review involved a preliminary report on the safety, clinical effectiveness and ethical considerations associated with retinal photography undertaken by health workers, including Aboriginal health workers, in rural and remote areas, with the photos then being read by ophthalmologists.

In gathering community perspectives using the literature we used the academic peer-reviewed literature and the grey literature of research reports dealing with diabetes management. We also included a survey of personal weblogs or blogs maintained by people living with diabetes. Blogs present a potentially valuable and readily available source of community views in the area of chronic disease. That they are a largely untapped resource is because of the recent emergence of the use of blogs as personal communication tools or 'online journals'. Blog portals for mass use in blog creation were only developed in 1999. As a consequence blogs are at present primarily the domain of the young; 94% of bloggers are aged <30 and over 58% are <19 years.⁴ At present most of the blogs are based in the USA, UK or Australia and blogging is limited to those with access to the technology on a regular basis. The Perseus survey in 2005 estimated 31.6 million blogs had been created worldwide,⁵ up from a total 4.1 million blogs in 2003.⁶ More than two-thirds of these are abandoned blogs but it is apparent that the number of active blogs is growing rapidly. The number which can be identified as 'diabetes'

blogs is still small but the wealth of material derived from a single blog chronicling the daily reality of living with diabetes, can be diverse, rich and distinctive.

Using the case study, we examined whether it is possible to use the literature both formal and informal to gauge community perspectives on a health technology.

Methods

Search terms that would identify published literature useful for providing community perspectives were selected within the categories shown in Table 1.

The search terms used in this study are very different to those used in the AHTA rapid review (see Table 1), in which the emphasis was on safety, cost and clinical effectiveness. Databases searched were Medline, Cinahl and Informit. Searches were restricted to English language and to the years 1996–2006, although earlier papers were occasionally sourced from papers published in that period. Google Scholar and the Australian Indigenous Health InfoNet (<http://www.healthinfonet.ecu.edu.au/>) were searched using the search terms: (diabetic retinopathy OR diabetes, screening, Aboriginal, report).

We realized early in the project that a narrowly defined search for patient perspectives on diabetic retinopathy screening would yield little information and it is apparent that people living with diabetes do not look at diabetic retinopathy screening in isolation but rather in relation to the overall management of their diabetes. Therefore, the search strategy went beyond a narrow focus on diabetic retinopathy screening to a broader perspective on diabetes management. Papers were selected on the basis that they either presented the perspectives of people living with diabetes through questionnaires, focus groups, personal stories or interviews or they presented data detailing the acceptance or uptake of screening or therapy associated with diabetes management (Table 2). Within this context it made sense to examine the relevance to the community of a siloed diabetes retinopathy screening programme and, how such a programme might sit in the competing demands for resources within diabetes management. Only papers describing empirical research with community participants were included: editorials and commentary pieces were excluded, as were opinion pieces from health personnel.

Although the AHTA rapid review was directed broadly at assessing ‘the use of retinal

Table 1 Search terms used for identifying relevant literature in journal databases

Category	MeSH term/keyword in this project	MeSH term/keyword in AHTA rapid review
Disease/disorder description	Diabetic retinopathy; diabetes mellitus, type 1 OR diabetes mellitus, type 2	Diabetic retinopathy
Who are the interested parties?	Rural population; Indigenous; Aboriginal; oceanic ancestry group; health services	Rural population; rural health; Indigenous
‘Umbrella’ terms describing the activity	Mass screening; telemedicine; vision screening	Health services
What are we trying to canvass?	Patient satisfaction; attitude to health; patient compliance; public opinion; health knowledge, attitudes, practice; patient acceptance of health care	
Methods that might be employed in canvassing views	Qualitative research; focus groups; interviews	

Table 2 Study population and research instruments used in studies presenting community perspectives on

Study	Study population	Awareness of risk	Instrument
(a) Awareness of risk			
Trento <i>et al.</i> 2002 ¹⁹	Italian (<i>n</i> = 130) and Welsh (<i>n</i> = 128) diabetes T1 and T2 patients	Poor perceptions of long-term risk of diabetes amongst patients. Group care in long-term awareness raising strategy improved perceptions of risk.	Questionnaire
Pasagian-Macaulay <i>et al.</i> 1997 ¹⁷	American women with diabetes (<i>n</i> = 150), 52% African American. County funded medical centre. Mostly low SES. 52% IDD	Patients' perceptions of diabetes self-care and knowledge of complications was poor. Knowledge of rationale for self-care and nature of eye exams was also poor.	Cross-sectional telephone questionnaire
Wong <i>et al.</i> 2005 ²¹	Australian Torres Strait Islanders with diabetes T2 (<i>n</i> = 67)	Patients' perceptions of diabetes self-care and knowledge of complications was poor	Focus groups & interviews
Funatsu <i>et al.</i> 2003 ²³	Japanese with diabetes T1 (<i>n</i> = 1333) 55% men	High knowledge of ocular complications with diabetes (98%) but only 70% had periodic ocular exams. Main reason given: those who did not have exams did not see themselves as personally at risk.	Questionnaire
Eiser <i>et al.</i> 2001 ¹⁸	English (<i>n</i> = 100) with diabetes T1 (<i>n</i> = 12) and T2 (<i>n</i> = 88)	Knowledge of causes of diabetic eye disease was poor. Clear reluctance to change diabetes management even with diagnosis of retinopathy.	Questionnaire
Port Lincoln Aboriginal Elders and Health Service Community ¹¹	Australian Aboriginal with diabetes from rural town (<i>n</i> = 16) and health service personnel	Patients' perceptions of diabetes self-care, understanding of importance of medication and knowledge of complications was poor.	Personal stories / group discussion
Clark and Hampson 2003 ²⁰	British healthcare professionals (doctors/nurses/dieticians) (<i>n</i> = 104). Patients with diabetes T2 (<i>n</i> = 100)	Differences between patients and health professionals as to perceptions about seriousness of diabetes and value of tight blood glucose control.	Questionnaire
Study	Study population	Compliance with screening	Instrument
(b) Compliance with screening			
Basch <i>et al.</i> 1999 ¹⁵	African American with diabetes (<i>n</i> = 280). Randomized to intervention (diabetes education) or control group	Nearly 50% of patients in intervention group reported a DR screen within 6 months compared with 25% of control group.	RCT
McCarty <i>et al.</i> 1998 ¹⁴	Australian urban population (<i>n</i> = 3271). With diagnosed diabetes (<i>n</i> = 162)	Nearly half of adults with diabetes in Melbourne not receiving adequate 2-yearly screening for DR	Interview

Table 2 (Continued)

Study	Study population	Compliance with screening	Instrument
Tapp <i>et al.</i> 2004 ⁴⁴	Australian urban and rural (<i>n</i> = 11 247) with diagnosed diabetes (<i>n</i> = 475)	77% of those with diagnosed diabetes reported an eye exam in past 2 years (study did not distinguish between eye exam and dilated fundus exam). 18% had never had an eye exam. High awareness (90%) of complications from diabetes.	Interview
Reda <i>et al.</i> 2003 ¹⁶	New Zealand Waikato District (<i>n</i> = 8172). Maori 20% Mobile retinal photo screening programme over 8-year period	Failure to attend screening higher in Maori and Pacific Islander populations (33%) compared with European (13%). Percentage of VTR fell dramatically (11.5–1.5%) over the intervention period.	Audit
Mak <i>et al.</i> 2003 ³²	Australian rural and remote population over 11 health services areas with diabetes (<i>n</i> = 165) Aboriginal (86%). Patients recommended for recall (<i>n</i> = 141)	Majority report DR screening in previous 2 years (58%). Wide variation between health services (35–88%). Repeat screening poor. Only 23% had complied by cut-off date. Re-screening overdue by 18–107 weeks (median 43 weeks).	Audit
Durkin <i>et al.</i> 2006 ³⁷	Australian Aboriginal remote (<i>n</i> = 1651) with diabetes	Of <i>n</i> = 92 requiring laser photocoagulation treatment for DR only 31 underwent treatment	Screening data from Eye Health Program
Study	Study population	Attitudes to compliance	Instrument
(c) Attitudes to compliance			
Clark 2005 ²⁴	Various		Synthesis/review
Skinner 2004 ²²	Various		Synthesis/review
Bachmann <i>et al.</i> 2003 ²⁵	English (<i>n</i> = 770) with diabetes T1 and T2	Least educated patients were more likely to have DR. This group see diabetes as having an adverse effect on social and personal life, are fearful about diabetes, are seen as less compliant by health professionals but do not see themselves as non-compliant	Cross-sectional questionnaire
Barton <i>et al.</i> 2005 ²⁶	Canadian Aboriginal with diabetes from Nuxalk Nation, British Columbia (<i>n</i> = 8)	Difficulties in making dietary changes and in exercising and unwillingness to give up traditional foods. Issues in conforming to pill taking regimen. Understanding of how medications worked was poor.	Qualitative in-depth interview
Port Lincoln Aboriginal Elders and Health Service Community 2002 ¹¹	Australian Aboriginal with diabetes from rural town (<i>n</i> = 16) and health service personnel	'Dominant story of fear'. Fear of amputation of a limb, renal disease or death was included in the stories but not the fear of blindness.	Qualitative/group discussion and collected stories

Table 2 (Continued)

Study	Study population	Attitudes to compliance	Instrument
Facey <i>et al.</i> 2002 ³³	British	Some patients do not like mydriasis.	Patient issues workshop
Hassler-Hurst <i>et al.</i> 2004 ³⁴	British adolescents type-1 diabetes (<i>n</i> = 30)	Pain described in association with tropicamide eye drops	Patient opinion on pain scoring scale
Lee <i>et al.</i> 1999 ³⁶	Australian urban and rural GPs (<i>n</i> = 253) with patient(s) reporting no DR screening in previous 2 years	59% of patients referred. 41% not referred. Reasons for non-referral conflicted with patient recollection. 79% of those referred for further screening complied.	Survey

T1, diabetes mellitus type 1; T2, diabetes mellitus type 2; IDD, insulin dependent diabetes; DR, diabetic retinopathy; VTR, vision threatening retinopathy; GP, general practice.

photography in rural and remote areas' it is well-recognized that the health burden of diabetes in rural and remote Australia falls disproportionately on Aboriginal people. Aboriginal people make up 24–64% of very remote populations in Queensland, NSW, WA, SA and NT⁷ and diabetes is more prevalent amongst Aboriginal population than the non-Aboriginal population (6% vs. 3.6% respectively).⁸ Therefore, we made particular efforts to source community perspectives from Aboriginal communities through directed searches particularly in Informit and the Australian Indigenous Health Infonet databases as described above.

Weblogs (or blogs) were also searched using blog search sites Google Blog Search (<http://blogsearch.google.com/>), Technorati (<http://www.technorati.com/>) and Blog Search (<http://search.blogger.com/>). Although these searches identified many blogs maintained by organizations, only 'personal' blogs were searched further. The Diabetes OC website (<http://diabetesoc.blogspot.com/>) was particularly helpful for identifying useful personal diabetes blogs. All personal adult types 1 and 2 diabetes blogs on the OC website were hand-searched using the terms 'eye' or 'retinopathy'. In total, 102 blogs dated December 2004 to September 2006 were hand-searched. Blogs were primarily used as an adjunct to the published literature and served to enhance the evidence offered by the peer-reviewed literature.

Findings

Almost all of the peer-reviewed references in Table 2 could have been sourced through Medline alone, providing the appropriate terms had been used. Possibly because in Indigenous health it is more common to take a holistic view of health, the specific MeSH search term, 'diabetic retinopathy', did not provide appropriate papers on Indigenous community views for inclusion in this study. Rather the MeSH search term 'diabetes mellitus' in addition to specific search terms for Indigenous population groups identified papers reporting Indigenous community perspectives on diabetes management including eye screening.

Google Scholar and the Australian Health InfoNet provided several relevant reviews of research which were not represented in the peer-reviewed literature.^{9–13} Weblogs provide insight into problems with screening and treatment compliance and for insight into the fear and distress associated with diabetic retinopathy laser treatment.

In some instances, this review of community perspectives provided similar information to that found with the AHTA rapid review but afforded a richer explanation of the issues. For example, it is clear from the peer-reviewed literature, that even with a highly proactive and accessible screening programme in place, many people may not access it.^{14–16} This was

mentioned briefly in the AHTA rapid review (p. 14).³ Our study was able to provide broader evidence of at least two underlying reasons for this failure to access available services. First, people with diabetes may not see themselves at risk of eye damage, possibly because they are asymptomatic until significant vision loss has occurred or due to a gap between patients' knowledge and health practitioners' assumptions about patient knowledge. Studies across Europe, and USA populations show that many people with diabetes have poor understanding of the disease, the reason for eye exams, the value of preventive measures, the rationale for therapy and the mechanisms underlying long-term complications.^{17–21} 'Grey' literature studies with Australian Aboriginal populations supported this contention^{9,11} and suggested that some health workers also have limited understanding of these factors.⁹

Secondly, the peer-reviewed literature shows that people coping with chronic disease may feel overwhelmed by the demands of the disease²² and categorize eye screening as low priority or may not see themselves as personally at risk.²³ Clark²⁴ reviewed professionals' vs. patients' perspectives on diabetes and reported that people with diabetes 'emphasize difficulties in the social domain and the impact of diabetes in their lives' whereas health professionals 'see diabetes as a pathophysiological problem'. It is clear from blogs but has also been reported in the formal literature that people do not see themselves as non-compliant but rather as making difficult choices in coping with chronic disease.^{25,26} Patients with diabetes also suffer from other illnesses and are advised to obtain screening for those conditions. Therefore, they may feel that they are always visiting a doctor (e.g. see Violet's diabetes blog²⁷).

Again, possibly because of the narrow focus of peer-reviewed literature, it is not possible to glean from this source what emphasis, if any, people place on the value of diabetic retinopathy screening. However, given the broad discussion of many other aspects of diabetes management in the grey literature and blogs, the absence of discussion about diabetic

retinopathy in these sources is revealing. For example, there is very little evidence in 'grey' reports or blogs that the risk of eye damage or blindness associated with diabetes is seen as a major concern amongst people with diabetes. The Port Lincoln Indigenous Stories study¹¹ does not mention eye complications and despite numerous blogs written by people with type-1 diabetes diagnosed 10–25 years ago, there are only a small number of entries about diabetic retinopathy or eye screening, suggesting this complication is seen as a low risk in the diabetic blogging population. For example, Morrone describes a fear of diabetic retinopathy that grows with time:

Every year, for the better part of the 45 min exam, I hold my breath. My eyes stare luminously at the circle on the wall as she shines the light in my eye, searching for my failure. Every year I wait for her sharp intake of breath. Morrone²⁸

Most bloggers, however, see diabetic retinopathy screening as one more 'exercise in torture'²⁹ and those blog entries that do refer to the risks to eyesight generally do so within the context of the wider risk of long-term diabetes complications – for example:

I live every single day with the fear of losing my eyesight or the sensation in my hands and feet.... Nicole P.³⁰

And one blogger with type-2 diabetes describing visiting an endocrinologist for the first time:

I sat in a room covered with many posters about diabetes complications. It would make even the most lax diabetic get there [sic] act together. Pictures of foot problems, retinopathy, neuropathy, and so many more that I just closed my eyes and said to myself, 'That will not be me. That is why I am here'. Whittier³¹

In contrast, the fear invoked by daily living with diabetes is commonly described in the grey literature and blogs. In type-1 diabetes blogs the fear of a hypoglycaemic episode is pervasive and the Port Lincoln study, incorporating the views of Aboriginal people with diabetes, describes a 'dominant story of fear' particularly the fear of amputation or death.¹¹

Occasionally, broader explanations for poor compliance with screening recommendations³² can be found in both the grey and peer-reviewed literature. For example, both a qualitative HTA report from the UK³³ and a journal article³⁴ indicated that patients may not like mydriasis use in screening because of the associated discomfort and blurred vision but it is a blogger who conveys best an experience of fear and discomfort:

I went to the eye doctor tonight. It has me pretty upset.

Every time I go, I have my eyes dilated, like a good little diabetic.

Then I sit there, without my contacts, blind for 10 min while the drops work.

I went into the room, and the doctor came in. He made the required small talk. I hate this part of the appointment...Then he starts the exam. He pulls out the little light, and starts looking. This time, he lingers longer on each eye longer than usual. So long, that my dilated eyes tear excessively, and I long to close them. He makes annoying worried noises that sent my panic level through the roof. Grasman³⁵

Similarly, although the peer-reviewed literature describes failure of the referral chain³⁶ and therapy uptake³⁷ in diabetic retinopathy programmes particularly in remote and rural regions, explanation of the underlying reasons is lacking. A single graphic blog about the experience of laser therapy describes a painful and uncomfortable procedure:

It definitely felt like someone was pricking me with a needle from behind my eye. Not a pleasant feeling, at all. Both eyes were watering and my ears were filling with tears. I could only stand 5–15 laser shots at a time before I'd need a brake (sic) from the procedure. Just a few seconds to catch my breath and to get some blood back into my white knuckles. Kevin³⁸

Descriptions about the nature of laser therapy were not found in the peer-reviewed literature, therefore, it is not clear if this is a universal or even common experience. Given the possibly unpleasant nature of the screening and treat-

ment and the poor understanding of the rationale behind it, peer-peer report of the experience of laser therapy may discourage others from complying with treatment but other factors, such as difficulty in accessing treatment services, may also be important in remote and rural communities.

Evaluating the sources: peer-reviewed literature, grey literature and weblogs

The traditional HTA search focus which is primarily confined to quantitative studies in the peer-reviewed literature provides good coverage of quantitative aspects of diabetic retinopathy screening, such as failure to access screening^{14–16,32} and failure of the referral process^{36,37} although discussion of these aspects in the AHTA rapid review was limited by the scope of the review. A broader focus on community perspectives in the literature search and the incorporation of qualitative peer-reviewed research and grey literature, as described in this study, allows discussion of the underlying reasons for such failures. In our study, this included consideration of the broader perspective of where diabetic retinopathy screening sits within the priorities of health resource management for rural and remote areas.

The absence of word limits for grey literature reviews means that a deeper examination of people's experience is possible particularly in qualitative research. This depth is even more apparent in blog discussions which describe in stark detail the hour by hour burden of managing diabetes; detail and depth which is absent in the 'snapshots' taken through interviews and focus groups. There is considerable evidence that people will disclose more information in an on-line environment compared with off-line qualitative research.³⁹

In addition, blogs highlight aspects outside the purview of research projects such as the broad consideration of the relentless nature of chronic disease or the isolated issue of discomfort in retinopathy therapy. In some cases, it is the absence of discussion that is revealing, such

as the lack of discussion about eye complications in discussion groups and blogs when other complications are mentioned frequently. Such a gap is less remarkable in the peer-reviewed literature where the focus of the discussion is directed by researchers.

The grey literature is particularly useful for sourcing Indigenous community views. Many studies with Indigenous people remain in the 'grey' literature of programme reports and do not reach the peer-reviewed literature. Although weblogs predominantly represent the experience of non-Indigenous, urban-dwelling people diagnosed with diabetes, some views presented in weblogs, such as the burden of day-to-day living with diabetes and perceptions of the risk of long-term complications, find parallels in surveys or qualitative studies from rural and remote populations including Indigenous groups.

Examination of weblogs may also be useful in providing insight on areas worth exploring in other diabetic patient populations. Although weblogs are limited by the lack of formal mechanisms of evaluation and validation, the informal peer review of fellow bloggers can be a powerful constraint and a correction instrument.

Inclusion of community perspectives in the review focus, as provided in this study, challenges the underlying assumption that provision of diabetic retinopathy screening is the best approach to reduce the level of diabetic eye disease in rural and remote populations in Australia and allows examination of how diabetic retinopathy screening sits within health resource management. Recent studies^{40,41} show lower overall incidence of diabetic retinopathy among Aboriginal people living with diabetes than in the overall Australian population, although the results were not age adjusted. However, higher incidence of vision threatening complications and faster disease progression were reported. Similar results were reported in New Zealand Indigenous patients.¹⁶

Our study provides evidence that suggests provision of diabetic retinopathy screening in rural and remote areas may meet considerable patient resistance to uptake. It is beyond the scope of this project to assess the cost effective-

ness of alternative approaches. However, there is some evidence to suggest that improved diabetes management *per se* may be a better use of scarce resources in these communities. For example, large-scale failure to diagnose existing diabetes cases occurs even in Aboriginal communities with well-established diabetes screening programmes;¹⁰ many Aboriginal people do not have glucometers to monitor glucose;²¹ therapeutic action on glycaemia in these communities may be poor⁴² and there is substantial undiagnosed diabetes in the Aboriginal population.⁴³ Given this evidence, it is possible that increased diabetes diagnosis and education, improved glycaemic control amongst diagnosed diabetics, structured diabetes education approaches or even support for Quit (smoking cessation) programmes or smoking prevention might deserve a higher priority than diabetic retinopathy screening as a means of reducing diabetic eye disease or diabetic complications in this population. Such programmes may well result indirectly in reduced eye complications but would also carry other positive attributes including reduction in other long-term diabetic sequelae, such as peripheral neuropathy, cardiovascular disease and renal damage.^{12,44} Siloed diabetic retinopathy screening may be less efficient with respect to resources and less amenable to populations than a one-stop-shop of a mobile integrated screening programme such as that provided in First Nation communities in Alberta Canada.¹³

Conclusion

This review shows that community perspectives on selected health technologies can be gauged from available resources in the academic and grey literature and that perspectives collected in this way can provide insight into whether the introduction of the technology would be acceptable to the community. It is also apparent that, for selected technologies, a richer account of the social, behavioural and ethical issues associated with its use may be valuable in supporting decision-making about funding (or withholding funding). A review of the literature

and weblogs can be used to predict barriers to use, possible harmful consequences and potential failure of supported programmes. Comparative analysis of alternate approaches to the problem addressed by the technology may also be investigated.

There are, however, important limitations to the use of the literature and weblogs in HTA. Many of the views we have collected in this exercise are not sourced from the rural and remote areas of Australia but rather are the views of urban North Americans or Europeans. Analysis of the social aspects of HTA must take into account the specific needs, culture and experience of the specific communities who will be impacted by the health technology. Further given the gulf between Indigenous and non-Indigenous populations in Australia, in terms of health outcomes and access to technology, it is obvious that in this case-study, where locally relevant literature is scarce, a review of the literature and weblogs cannot replace targeted community consultation. However, provided the limitations are recognized the methods employed in this study can provide a useful source of evidence for targeted research and HTA.

With the health technology examined in this report, weblogs proved useful for enhancing the evidence gauged from the broader literature. In select topics, such as the discomfort associated with screening or the daily demands imposed by living with diabetes, the perspectives gathered from weblogs were similar to those sourced from reports and literature reviews. In some areas, such as the experience of laser therapy, weblogs provided insight not available in the published literature.

To our knowledge, this is the first use of blogs in HTA. The number of weblogs actively maintained by people with diabetes is still small but is growing exponentially.⁵ As weblogs become more widely accepted, the user population ages, costs fall and the computer technology becomes more accessible, it is probable that on-line diabetes communities will continue to grow. Whether blogs will be useful for providing insight into community perspectives for less

common diseases than diabetes requires further investigation. For example, we have been able to find weblogs maintained by people who write about living with breast cancer,⁴⁵ sensorineural hearing loss,⁴⁶ cystic fibrosis⁴⁷ and muscular dystrophy.⁴⁸ The development of many communities of bloggers with shared experience is probably inevitable and may be useful for providing community perspectives on most health technologies in the future.

There are a number of ethical issues that arise when blogs are used as sources of 'data' for research including the blurring of public-private boundaries as blogs often present intimate personal details on a public site. In addition, on-line communities may resent the apparently voyeuristic intrusion of researchers into what may be seen by participants as an important chronic-disease support network. The recent emergence of blogs means that the ethical issues associated with their use in research have not been explored and an examination of these issues in future research would be useful.

Blogger, Kerri Morrone, describes the disease which governs her life in these terms: 'Diabetes doesn't define me but it helps explain me',⁴⁹ Any health technology that is not accepted by the people, who will use it, will not be effective. This paper shows that community perspectives drawn from the virtual community of academics, bloggers and community health researchers can 'help explain' the experience of living with chronic disease. Acknowledgment of these perspectives will improve the quality and the value of HTA.

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Conflicts of interest

None.

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