

What is already known on this topic

The volume and complexity of evidence from research makes it inaccessible to busy practitioners, who often lack sophisticated search and appraisal skills

Evidence is usually only available for part of the sequence of decisions and actions in real life clinical problems

Evidence might indicate what works but not how to do, it and it cannot take account of local context, resources, and politics

What this study adds

Bringing researchers and practitioners under the same "virtual roof" in an accessible, low technology email forum can help bridge the gap between research and practice

Soft networking enables knowledge for evidence based health care to be personalised and made meaningful through informal social interaction

Skilled staff can encourage a strong culture of support and reciprocity within the network and can target messages to individuals with matching interests

potential benefits to be realised, healthcare organisations will need to provide an enabling environment for participation. Because of the informality of networking, particularly virtual networking by email, there can be a danger that it is perceived as, at best, a marginal activity to be squeezed in if time permits rather than an integral component of the evidence into practice cycle.

We thank David Evans, Wendy Zhou, Natasha Karpava, and the CHAIN members who contributed to the evaluation, and

Olympia Kyriakidou, Janet McDonnell, Jeanette Buckingham, and two reviewers for helpful advice on earlier drafts of this paper.

Contributors: See bmj.com

Funding: NHS research and development programme.

Competing interests: None declared.

Ethical approval: Not required.

- 1 Bero LA, Grilli R, Grimshaw JM, Harvey E, Oxman AD, Thomson MA. Closing the gap between research and practice: an overview of systematic reviews of interventions to promote the implementation of research findings. The Cochrane Effective Practice and Organisation of Care Review Group. *BMJ* 1998;317:465-8.
- 2 Grol R. Improving the quality of medical care. Building bridges among professional pride, payer profit and patient satisfaction. *JAMA* 2001;286:2578-85.
- 3 Needham G. Research and practice: making a difference. In: Gomm R, ed. *Using evidence in health and social care*. London: Sage, 2000.
- 4 Wyatt JC. Management of explicit and tacit knowledge. *J R Soc Med* 2001;94:6-9.
- 5 Guba E, Lincoln Y. *Fourth generation evaluation*. London: Sage, 1989.
- 6 Kushner S. The limits of constructivism in evaluation. *Evaluation* 1996;2:189-200.
- 7 Patton M. *Utilization-focused evaluation*. London: Sage, 1997.
- 8 Spencer L, Ritchie J, Lewis J, Dillon L. *Quality in qualitative evaluation: a framework for assessing research evidence*. London: Cabinet Office, 2003.
- 9 Parlett M, Hamilton D. Evaluation as illumination: a new approach to the study of innovative programmes. In: Hamilton D, ed. *Beyond the numbers game: a reader in educational evaluation*. London: Macmillan, 1972.
- 10 Nonaka I, Takeuchi H. *The knowledge creation company: how Japanese companies create the dynamics of innovation*. New York: Oxford, 1995.
- 11 Ferlie E, Gabbay J, Fitzgerald L, Locock L, Dopson S. Evidence-based medicine and organisational change: an overview of some recent qualitative research. In: Ashburner L, ed. *Organisational behaviour and organisational studies in health care: reflections on the future*. Basingstoke: Palgrave, 2001.
- 12 Nonaka I. A dynamic theory of organizational knowledge creation. *Organ Sci* 1994;5:14-37.
- 13 Bate SP, Robert G. Knowledge management and communities of practice in the private sector: lessons for modernizing the NHS in England and Wales. *Public Admin* 2002;80:643-63.
- 14 Edwards N. *Clinical networks: a discussion paper*. London: NHS Federation, 2001.
- 15 Fenton E, Harvey J, Griffiths F, Wild A, Sturt J. Reflections from organization science on the development of primary health care research networks. *Fam Pract* 2001;18:540-4.
- 16 Urquhart C, Yeoman A, Sharp S. NeLH Communities of practice evaluation report, 2002. Department of Information Studies, University of Wales Aberystwyth. www.nhsia.nhs.uk/nelh/pages/documents/cop.doc (accessed 28 Apr 2004).
- 17 Granovetter M. The strength of weak ties. *Am J Sociol* 1973;78:1360-80.
- 18 Wenger E. *Communities of practice: learning, meaning and identity*. Cambridge: Cambridge University Press, 1996.
- 19 Nonnecke B, Preece J. Silent participants: getting to know lurkers better. In: Lueg C, Fisher D, eds. *From Usenet to CoWebs: interacting with social information spaces*. London: Springer, 2002.

(Accepted 2 April 2004)

INFOPOINTS**International online discussion lists on chronic myelogenous leukaemia**

Joana D Ramos, Anjana Rai-Chaudhuri, Robert W Neill

The rise of the internet as a communication tool has resulted in the creation of ehealth interfaces as a service for those with illness. We describe how two online discussion lists for patients with chronic myelogenous leukaemia affect the health care of patients both individually and worldwide.

The Chronic Myelogenous Leukaemia International Support Group was formed in 1998 by Robert Neill after his mother was diagnosed as having the condition. The list has 1500 subscribers and averages 28 new postings a day. A major feature of list

discussions is the sharing of information and experiences of patients undergoing treatment for disease (figure).

In 1999, imatinib (Novartis), a drug in the early phase of clinical trials for chronic myelogenous leukaemia, was in short supply. The chronic myelogenous leukaemia list petitioned Novartis to increase production, resulting in the opening of 19 additional clinical trial centres, giving access to patients, many of whom had no other treatment options.¹ The sharp rise in advocacy in messages posted on the list in 1999 reflects this mobilisation of patients (figure). This

Cancer Resources and Advocacy, 7303 23rd Avenue NE, Seattle 98115 WA, USA

Joana D Ramos
consultant

Asian Chronic Myelogenous Leukaemia Support Group

Anjana Rai-Chaudhuri
founder

continued over

BMJ 2004;328:1178-9

Chronic Myelogenous Leukaemia International Support Group
Robert W Neill
founder

Correspondence to:
J D Ramos
jdramos3@comcast.net

shows how an online support group played a major part in promoting access to treatment.

Another topic frequently discussed on the list was the high global price of imatinib and related access problems, especially in developing countries. Again, there was an increase in patient advocacy activity in 2002. The intensity and content of concerns over the topic were such that they became the subject of media attention.²

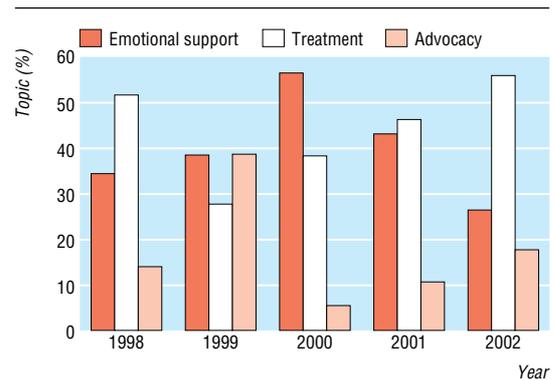
The Asian Chronic Myelogenous Leukaemia Support Group was formed in February 2003 by Anjana Chaudhuri, a care giver based in Singapore, whose husband was diagnosed as having the condition.³ This list has 240 subscribers and averages 34 new postings a day.

To study the impact of online support lists for chronic myelogenous leukaemia on the health care of individual patients, we conducted a survey of 35 patients from the Asian support group (table). Although the number of responses is relatively small, this is not unusual in surveys of this nature.⁴

Most patients (74%) joined the list to obtain information on treatment. All patients thought that their mental wellbeing improved because of the camaraderie from peers. A large proportion viewed the list as a lifeline and a better source of support than family. Most preferred online support to group meetings because of its ability to transcend boundaries of time and geography and to be constantly available. Most (77%) patients reported that knowledge gained from online support groups enabled them to make better decisions about treatment.

Responses to questions asked in survey of 35 patients who use Asian Chronic Myelogenous Leukaemia Support Group discussion list

Question and choices	No (%) responding (n=35)
What do you gain most from online support groups?	
Emotional support	9 (26)
Information on disease	6 (18)
Information on treatment	20 (56)
Do you believe that support groups have increased your mental wellbeing?	
Yes	35 (100)
No	0
Do you feel less stressed or depressed because you can share your problems with others in the same boat?	
Yes	31 (89)
No	4 (11)
What do you view online support groups as?	
Lifeline	13 (37)
Additional support with friends and family	22 (63)
Do you think that online support groups have influenced your treatment decisions?	
Yes	27 (77)
No	8 (23)
What kind of support group do you prefer?	
Online	21 (60)
Face to face	3 (9)
Both	11 (31)
Are you richer in friends because of the support groups?	
Yes	30 (86)
No	5 (14)
Do you feel that fellow members empathise better than your spouse and family with your situation?	
Yes	27 (76)
No	8 (24)



Random sampling of topics covered over five years by Chronic Myelogenous Leukaemia International Support Group

A major drawback of ehealth applications such as these support groups is their inability to serve as a public health interface on an international scale. Because participation requires internet access and literacy in English, participation from developing countries, with the most serious access problems to medicines, has been limited. The groups, however, are important for increasing both patient education and awareness of global issues affecting treatment. The lists put a human face on access difficulties and hopefully will increase broader advocacy efforts by those in countries where treatment, particularly for cancer, may often be viewed as a personal concern. This new kind of community has potential as a positive aspect of globalisation.

The Chronic Myelogenous Leukaemia International Support Group can be found at groups.yahoo.com/group/cml, and the Asian Chronic Myelogenous Leukaemia Support Group can be found at asia.groups.yahoo.com/group/AsianCMLSupportGroup.

Contributors: ARC conducted the survey and produced the table. All authors wrote the paper. ARC will act as guarantor for the paper.

Funding: None.

Competing interests: None declared.

Ethical approval: Not required.

- Boudreau D. Patient power. www.novartis.com/pathways/content/vol2num4/archive/artic2.html (accessed 10 Sep 2003).
- Strom S, Fleischer-Black M. Company's pledge to donate a drug is falling short. *New York Times* 5 Jun 2003;A1:C11.
- Chua Hian Hou. Virtual lifeline: a leukemia patient's desperate on-line search for a cure saved his life. *Computer Times* 8 Jan 2003. (http://it.asia1.com.sg/specials/spotlight20030108_003.html)
- Pew Internet and American Life Project. Vital decisions: how internet users decide what information to trust when they or their loved ones are sick, 22 May 2002. www.pewinternet.org/reports/toc.asp?Report=59 (accessed 8 Dec 2003).

How electronic communication is changing health care

Webchat

At 11 am local UK time, Thursday 20 May, the editors of this theme issue will be hosting a one hour webchat devoted to the topic.

Go to <http://quest.bmj.com/chat> a few minutes before it starts to read the rules of engagement and register.