SEA-AIDS

Electronic networking among HIV/AIDS organisations in Asia Pacific

For further information, please contact:
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Quick introduction

- 1996 – 2002
- Demonstrated the potential of electronic networks to strengthen exchange and partnerships on a previously unimagined scale
- >2,500 forum participants
- Cost-effective
- Training is cheap
- Access rapidly expanding – among key players
E-mail Forums - the basics

.....And members can answer directly or through the forum
I thank the two people who commented on my question. Assuming that the first response is correct, this would mean that people in Thailand will not receive the best proven diagnostic and therapeutic means of treatment, should they get sick as a consequence of their participation in these trials. This violates the current stipulations of the Declaration of Helsinki in this regard.

The local standard of care strategy is unacceptable. There can be little doubt that people will get infected and sick (even if the vaccine should work at a 100% success rate, which is very unlikely). To provide these people with anything less than the best available treatment is precisely what I meant when I asked whether people try to deal with these people on the cheap. Dual treatment, is, at least as far as I know, a substandard treatment that patients in Australia, the US and other developed countries would not put up with.

The reason for this ethical responsibility of the sponsoring agencies (commercial and UN-related) is that the Western intervention (i.e. Western researchers, Western companies) will result into these people taking risks in the first place. Hence they have the ethical responsibility to provide the best treatments available. Availability here cannot be defined as what is locally available, but rather, what would be available to sick people in, say the US and Geneva where the push for these trials is organised.

I wonder whether UNAIDS Dr Esponza, who was near ubiquitous on just about every vaccine panel and who is to a large extent the driving force behind these trials, could comment on whether the information provided by the Australian conference delegates is correct.

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and they can be reviewed through the internet too
Through the internet you have options like ‘reply’, ‘forward this message’, and ‘post a new message’ etc.
What do we know about forum members?

- NGOs: 40%
- Researchers: 29%
- Universities: 25%
- Governments: 19%
- UN agencies: 15%
- PWA groups: 11%
- Other CBOs: 11%
- Private sector: 7%
- Women’s Groups: 7%
- Doc Centres: 8%
Forum activity
What do members discuss?

A – Requests for information or assistance
B - Responses to a specific request
C – Current news/issues
D – Sharing of opinions/ discussions around a specific topic
E – Announcements of resources
F – Information on on Conferences/workshops/seminars/events etc
G – Other
February 1996 (n = 7)

- Information requests: 29%
- Responses to requests: 29%
- Other: 42%
March 1999 (n = 72)

- Responses to requests: 25%
- Information requests: 19%
- Current news: 14%
- Discussion: 27%
- Announcements: 1%
- Conference information: 10%
- Other: 4%
November 1999 (n = 30)

- Conference information: 84%
- Discussions: 7%
- Announcements: 3%
- Current news: 3%
- Requests for information: 3%
May 2000 (n = 37)

- Current news: 31%
- Responses to requests: 19%
- Discussions: 16%
- Announcements: 16%
- Information requests: 8%
- Conference information: 5%
- Other: 5%
February 2001 (n = 17)

- Conference: 29%
- Information Requests: 6%
- Current news: 12%
- Discussion: 24%
- Announcements: 29%
Are discussions visible to other forum members?

Visible discussions on a forum

Direct contact between members outside forum: invisible

To take part in this kind of one-to-one networking outside the forum.....

...you need to know who has the same issues or concerns.
We asked forum members: Have e-mail forums helped you find people working on the same issues or topics as you?

- Yes, many times 17%
- Yes, occasionally 69%
- No 12%

The members of e-forums report an overwhelming "YES"
Nice to meet you...

... in person - finally.

Also known as the:

“Oh, so you’re .......”

“Oh, you’re younger/older than I thought”

“Oh, you’re a man!”

“What did you think I looked like?”

syndrome
So the value of SEA-AIDS...

...lies not so much in the amount of information exchanged........

........ as the way it brings people together to share their own information, opinions and experiences on common objectives and needs
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Stigma and HIV/AIDS in Africa (6 months)

- Desk research
- Forum membership drive
- Key resource people
- Focus groups in-country

Forum dialogues (n=1350)

Bibliography
Who controls the majority of discourses on HIV/AIDS in 2001?

Discourses are mostly channeled through information systems and meetings:

- Publications, newsletters
- Mass media coverage
- Conferences and other face-to-face meetings
- The internet & web sites
Publications and newsletters

- Writers and editors
- Large international organisations
- Private sector (e.g., pharmaceutical and publishing)
- Industrialised countries?
- A small number of people
Mass media coverage

- Media organisations (e.g., editors, journalists, advertising managers)

- Large international organisations (e.g., through press releases and high-profile speeches)

- Industrialised countries

- A small number of people
Conferences and other face-to-face meetings

- International Advisory Boards
- International/national societies (e.g., IAS, ASAP)
- Local organising committees
- Conference sponsors
- Industrialised countries
- A small number of people
Who controls the majority of discourses on HIV/AIDS in 1999?

- Industrialised countries
- A small number of people

So who sets priority themes for electronic networks on HIV/AIDS?
The forum members

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Benefits

- Information exchange and discussion
- Fostering new partnerships between members
- Raising local and national priority issues
- Input and content from affected communities
- Promoting self-representation;
- Shifting agenda-setting into the hands of communities most affected by the epidemic;
E-networking – To do’s

- Most electronic forums are still used for dissemination and not discussion among members – little bottom-up content
- There is still a lot of confusion between:
  - information technology, exchange of content, and networking among people
- National/regional USE, but not MANAGEMENT – so again not fully bottom-up
E-networking – To do’s

- Uneven access to e-mail (by country, sector, capital/provincial & status)
- Single language – (Thai, Chinese)
- Information overload & duplication
- Small number of ‘active’ participants
- No good ‘road map’ of resources;
Sometimes the simplest tools can get you from A to B
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(additional slides just in case I need them)
Examples of moderation steps

- Basic member services - simple member questions about forums, refer to archived discussions etc.
- Referral services – refer requests to more appropriate information sources (student projects etc.), suggest suitable institutional contacts, explain confidentiality guidelines, frequently asked questions; pass on replies directly to original authors
- Edit for timeliness, readability, spelling etc., explanation of acronyms, de-jargon, & add contact details of authors
- Reply to authors requesting clarification, further information or reference materials
- Cross-reference to previous postings, discussions or other events/publications – look for consistency of content, contrasting views etc.
- Add moderator comment, analysis, summarise main points, ask public questions

Content moderation → increasing content relevance and ‘density’
Increasing content 'density' to forum users

Moderation steps

Background reading/info
Key Correspondents
Invite comment

Moderation increases content 'density' and relevance to users
Postings to forum users
Without moderation, content density and relevance stay at this level.