



**EDC-22071 KOM2002/27938**

**Groupware for Distributed Content Production**

**KOM2002**

## Community Outreach and Prevention Network Requirements, Information Structure and Policies

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<b>Abstract (for dissemination)</b>	<p>By "Community Outreach" is meant how to reach other people than psychological and medical experts, such as people with psychological problems, their relatives and friends, teachers, social workers, politicians, etc.</p> <p>Such people will be reached through informational pages, forums, ask-the-expert pages, newsletters and maybe also chats.</p> <p>Important issues are how to avoid and handle abuse and anonymity (protection of privacy) for non-experts using our services. Different Web4Health language regions may choose different policies depending on the differing culture in different parts of Europe.</p>

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## **2 Executive summary**

By “Community Outreach” is meant how to reach other people than psychological and medical experts, such as people with psychological problems, their relatives and friends, teachers, social workers, politicians, etc.

Such people will be reached through informational pages, forums, ask-the-expert pages, newsletters and maybe also chats.

We will not market this until we have something working, probably 1 July 2003. Testing on smaller, selected groups, can however be done before this date.

Important issues are how to avoid and handle abuse and anonymity (protection of privacy) for non-experts using our services. Different Web4Health language regions may choose different policies depending on the differing culture in different parts of Europe.

## **3 Introduction**

This is a living text, the policies will be revised as needed from experience during the project. Also, the detailed policies will be adjusted to the needs of each language region, and this document at this time does not contain the specific policies for the French and Spanish language regions.

## **4 EU Guidelines**

We are aware of the EU “Guidelines For Quality Criteria For Health Related Websites” [EU1] and will adhere to these.

## **5 People to reach**

Here is a list of people, whom we want to reach with our information:

1. People with psychological problems.
2. People risking to get psychological problems, such as for example for eating disorders, adolescents and some professionals, such as actors, artists, models, dancers, athletes, gymnasts.
3. Relatives and friends of people with psychological problems.
4. Medical doctors and psychotherapists.
5. Teachers, social workers, nurses, and other people, who may have professional relations with people with psychological problems.
6. Politicians whose decisions can influence the risks for psychological problems.
7. Associations and other people with special interest in how society can cause psychological problems.
8. Photographers, copywriters, authors, journalists and other people whose products can influence the risk for psychological problems positively or negatively.

9. Psychiatrists, psychologists, psychotherapists, who treat people with psychological problems.
10. Researchers in psychiatry and psychology.

To prevent psychological problems, we want to reach all these groups. This does not mean that we have to develop complete different sets of information for each group.

## 6 How to reach people

Web4Health will employ the following tools to reach people:

A **web-based subject tree** with information about psychological problems.

A **natural-language question answering system** with the same information as in the subject tree.

**Ask-the-expert areas**, where people can send questions about psychological problems. The questions are monitored by experts and published anonymously together with the answer from the expert.

**Forums** (non-same-time discussion groups) on psychological problems.

Maybe also **chats** (same time discussion groups).

### 6.1 Use of Search Engine Optimisation Methods

Particular properties of the Internet is that you have small chances of forcing people to read information. They will read information, if they want to read it. And they will want to read it if the information is prominently shown in Yahoo, Google and Altavista.

Yahoo, Google and Altavista provide some ways of paying for advertisement, but people generally prefer to read the non-paid information more. And the non-paid information, especially in Yahoo and Google, is dependent on the quality of the information you provide. To get many people to read your web site, you simply have to produce a very interesting web site with information people want to read.

Search engines rate web pages by counting the number of links to them from other sites. Links from good sites are more highly valued. In practice, this means that the best way to get highly rated by search engines is to produce very good web sites.

So in order to succeed with prevention on the Internet, we have to produce high-quality web sites with high-quality information which people will want to search for.

Forums and chats have the advantage that if they succeed, people will come back more than once and read your information, while static web pages are usually only visited once or a few times by each person. Also the natural-language question-answering system might, if it provides a very large selection of answers, get people to come back more than once with new questions.

An additional search engine optimisation technique is to include in the title and text certain key phrases, which are repeated multiple times. Key phrases should be phrases which people use when searching the web, such as “treatment of anorexia”. Search engines sort listings partly on how often key phrases occurs in the pages.

## 7 Dissemination

In order to make Web4Health known and get users, dissemination efforts will be needed. We will, however, *not* do any dissemination efforts until we have a well-working first version of the Web4Health web site, including forums, newsletters, subject tree and natural language query service. This is expected to be 1 July 2003. Before that time, the Web4Health web site will be running, but with some sections marked as “under development”.

## 8 Software requirements

This section provides a list of the types of software that could be used.

### 8.1 Fact sheets (=FAQ pages) and natural language question answering

The subject tree structure need not be a hierarchical structure, the same item can appear in more than one place in the subject tree. The link lists in the subject tree will be produced by manually editing static web pages.

The leaves in the subject tree and the answers to the natural language question answering system will be produced in a common, XML-compatible format, from which both the documents for the subject tree and the answers to the questions can be generated automatically.

The natural language question answering system will use a set of questions. Each question will refer to an answers page. More than one question can share the same answers page. The questions will consist of manually selected keywords from four groups of keywords for each question: Required words, priority words, optional words, words not allowed. Each word can be specified with a set of synonyms. The actual questions given by users and the response they get from the system will be logged. Users will also be able to indicate their satisfaction with the response, this will also be included in the log. This log file will be used to increase the quality of the question-answer data base.

### 8.2 Forums, mailing lists and newsletters

Forums can be open (to anyone) or closed and open only to specified people. There can be access controlled, closed groups, whose members are allowed to join forums open only to them.

Some open forums will experimentally be automatically translated between European languages supported by the Systran language translation engine.

Closed forums can be used for experts and can also be used for closed groups of patients. Note, however, that closed forums for groups of patients should probably be much larger than ordinary group therapy groups. Ordinary, face-to-face group therapy groups typically include 4-8 people, but the group dynamics of forum usage means that the best group size is probably 30-50 people. Forum discussions in smaller groups tend

to die out because of inactivity, the “critical mass” effect [Palme, 1995] (see Appendix B: Critical Mass Effect on page 13).

Ask-the-expert areas and newsletters are so-called moderated forums, where contributions have to be approved by a moderator before publication.

Communication with the server will be encrypted using SSL.

## 9 Abuse issues

We do not know if there will be abuse of KOM2002, but this is possible. By abuse is meant that people write offensive and disruptive messages which cause other people to stop participating and which also may lead to bad publicity and even legal actions against KOM2002 or its users.

### 9.1 Examples of Abuse

Examples of some known abuse cases:

1. KOM version 5 had in 1986 about a thousand regular users. One new user X got infatuated with the system, wrote many times more messages than anyone else. This user had a supercilious attitude to the other users, implying that he knew everything much better than anyone else. As an example, there was a forum for people with the Christian faith. His participation in this forum enraged the other participants and hindered their previous usage to such an extent that this forum was split into two forums. A new forum, “Friendly Christians” was open to all members except this person.

Later on, user X used the system to distribute rumours about public people to such an extent that one of them prosecuted him for slander, and the court decided that he had to pay 15000 SEK (about 1700 Euro) in damages.

The publicity around his usage of the system also caused an organisation who had paid for much of the usage of the system to stop using the system.

2. Seniornet Sweden had a guest book, where visitors could anonymously participate. This was misused by people saying nasty things to each other to such an extent that they had to stop anonymous participation.

3. KOM was used, together with mailing lists and Usenet News, for risk experts to communicate with non-experts on risk assessment and research. This worked well for about a year. Then one single individual entered and started to write long, rambling and incoherent messages mainly discussing whether God exists or not. His participation caused many of the other participants to leave the forum, and caused the whole activity to stop.

4. Senior Online in Germany had been using the KOM 2000 chat facility. The chat facility in KOM 2000 allows people to put pictures in chats. Some people used this to post chat messages with animated hard-core pornography, which caused many other participants to take offence.

These are just examples, more cases have been reported in different European countries.

## 9.2 Abuse, Moderation and Anonymity

If all communication is pre-moderated – such that a moderator reads and approves all messages before they are published – then abuse is difficult. Only very clever hackers are able to circumvent the security.

However, pre-moderation has severe disadvantages, it reduces the interactivity and spontaneity of the interaction to a large degree.

In Web4Health, we have to let people with psychological problems and their relatives and friends to participate anonymously. This is known to increase the risk for abuse.

## 9.3 Actions to Reduce the Risk of Abuse

Action	Discussion
Require all users to accept usage rules before being accepted in forums and chats	May at least make it easier to throw out those who do not obey the rules.
Use only pre-moderated forums.	Reduces severely the spontaneity and interactive in forums with less than about 100 participants. In forums with hundreds of participants, pre-moderation is usually necessary to reduce the large amount of irrelevant messages.
Allow moderators to remove unsuitable contributions.	A less restrictive method which may be better than pre-moderated forums for smaller forums (less than about 100 participants).
Allow moderators/ administrators to forbid certain individuals from using the forum and chat facilities.	This is probably the most effective way of handling individuals who repeatedly abuse the services.

To forbid certain individuals from using the facilities has some technical problems. There is no 100 % sure method of stopping such individuals from coming back again under new names. Here are some technical methods with discussion of their usability:

<b>Action</b>	<b>Discussion</b>
Stop a user from using his login name and password.	Will not stop the same person coming back under a new name.
Set a permanent cookie in the computer of the user.	Only works if a single person uses a single computer. If several people use the same computer, they will all be stopped, even if only one of them abuses. If one person uses different computers, that person can continue to abuse the services.
Store the IP number of a disruptive user.	Will only work if the user's computer has a permanent IP number. Many Internet users, however, have dynamically allocated IP numbers or their actual IP numbers are hidden behind firewalls.
Stop a whole series of IP numbers.	To stop a single individual, all individuals using the same ISP (Internet Service Providers) have to be stopped from participating.
Find the real identity of users through their ISPs, and ask their ISP to cancel their accounts.	Will only work if the abuse is illegal usage or against the abuse rules of the ISP involved.

## 9.4 Anonymity and Pseudonymity

People with psychological problems, their relatives and friends, will be able to participate anonymously. This means that their name will not be divulged to anyone, except when required by law or as a last effort to stop misuse of Web4Health. Anonymous users will still have a secret user name known only to them (a pseudonym) and a password associated with this name.

By anonymity is meant that users can write messages without author indication on the message.

By pseudonymity is meant that users can choose secret names, perhaps known only to themselves, when writing messages.

By quasi-pseudonymity is meant that the computer stores some information about who the user is, but does not show this information to anyone. A privacy policy should clearly indicate in what cases the anonymity will be broken, for example only if ordered by a court of law or if severe abuse has continued despite warnings.

There is no 100 % secure and reasonably easy to use method to implement quasi-pseudonymity. One common method is that every new user must have an e-mail address, and that the user has to confirm his identity via response to a message sent to this e-mail address. Sometimes this is combined by not allowing e-mail addresses from services like Hotmail, which cannot identify the user. The disadvantage is that many casual Internet users cannot participate, since they do not have any such e-mail account.



Also, people with psychological problems may feel that their privacy is not well enough protected if the computer knows the real identity behind the pseudonym.

## **10 Policies**

### **10.1 Management of the Web4Health Web Site**

There will be two web sites, one for testing and one for production. Only the production site will be intended for people outside the project. The testing web site will have the same structure, but will contain new items not yet ready for publication on the production site.

When any partner without editorial discretion puts up at the test web site, a new or revised proposed web page for the official web site, partners should reply within four weeks, indicating their acceptance or rejection of the page.

Any partner who puts up a new or revised English-language page should notify the other partners of this. (This may be done automatically by the software.)

The project has decided to have its website in Swedish, Italian, German, Greek and Dutch. The Dutch website might not contain any natural-language question-answering service. We will also have an English-language site for exchange of information between partners and for reaching people not speaking any of the languages of our partners. Some facilities may not be available on the Dutch English site.

KTH will run the project web site on KTH servers, unless one language region wants to run it on their own servers. Each language area within the web site will be managed by partners from that area, except the English area which will be jointly managed by all the partners.

This web site will contain the following:

- Information about Web4Health
- Partners
- Answers to questions (FAQs)
- Disclaimer
- Links
- Forums and maybe chats

### **10.2 Access to forums and chats**

These policies for forums and chats will control who may participate by reading and writing, and rules for protection of the privacy of patients, their relatives and friends. The policies are also not fixed for all time, they can be changed as needed. For example, if there is problem with abuse in a forum, that forum can be changed to moderated status, after some time, its status can be changed back to non-moderated again.

Psychological problems forum: One or more general discussion group on psychological problems, available to anyone. It is important not to start too many forums, since this may cause users to spread out across the forums, so that none of them gets critical mass

size, see Appendix A. We may however have different forums for different kinds of psychological problems. This forum can switch format from moderated to non-moderated depending on experience and if abuse problems occur.

If the activity gets large, we will when needed split any of these forums into one or more subforums.

Ask the expert: An area where anonymous questions are published with expert answers.

Chats may be tested on an experimental basis. Chats will only run at special announced times, and will be monitored by an expert from Web4Health.

The following rules for participation will be made available to all users of Web4Health forums and chats. The text below is draft text, the final texts may be modified as needed from experience with usage of Web4Health.

### **Rules for use of Web4Health**

Web4Health is intended for serious exchange of information and experience on psychological problems. If you want to discuss your own or your friends' or relatives' problems, you can participate pseudonymously (your real name is secret), but you still have to adhere to these rules.

- Be nice and respectful to each other, do not say nasty, threatening or defamatory things.
- You may not use Web4Health to say illegal things, such as racial agitation, pornography, slander, etc. or to write information which is known to be false.
- Treat information, which you get about other people in Web4Health, as information given in confidence. Do not copy or forward the information outside of the forum where you read it.
- Do not write anything in forums in Web4Health, which you want to keep confidential.
- Be careful with the use of irony, people will easily believe that you mean what you write. Mark irony with ":-)".
- You may not use Web4Health for commercial marketing without permission from the Web4Health maintainers.

Web4Health reserves the right to remove contributions which do not adhere to these policies.

If you do not adhere to these rules, we may cancel your Web4Health account. If you participate pseudonymously, we will try to cancel your account without identifying who you are.

Web4Health reserves the right to remove unsuitable contributions from forums and chats.

You can make a complaint against abuse of Web4Health by writing e-mail to [cmc@dsv.su.se](mailto:cmc@dsv.su.se).

The following Privacy statement will be made. The text below is draft text, the final texts may be modified as needed from experience with usage of Web4Health:

### **Privacy statement**

If you want to learn about or discuss your own or your friends' or relatives' problems, you can choose to participate in Web4Health pseudonymously (with your real name secret). Other users must register using their real names.

If you choose to participate with your name, Web4Health will give you a password, which you can use so that other people cannot participate using your name.

If you choose to participate pseudonymously, you will be asked to select a secret name, a pseudonym. If you keep this name secret, other users will not know who you are. You will still have a password, so that other people cannot participate using your pseudonym.

If you indicate that you want your e-mail address to be kept secret, then we will not divulge your e-mail-address to anyone.

We will do our utmost to preserve the secrecy of your pseudonym. We may have to break your secrecy if the police or a court order requires us to identify you.

If you misuse your account, we may cancel your access to Web4Health, but still without identifying who you are. If we have cancelled your account, but you continue to misuse Web4Health, then we may have to identify who you really are in order to stop your misuse of Web4Health.

Web4Health may be used for research on psychological problems by Web4Health partners. The researchers will however not know the real name behind your secret name (pseudonym) without your explicit permission.

Other researchers may not use Web4Health for research without approval from the Web4Health consortium.

## **11 Medical Ethics Issues**

### **11.1 Clinical Evaluation**

Some parts of the Web4Health services will be evaluated clinically. Other parts may be evaluated in other ways.

### **11.2 Patients**

Patients will be asked if they want to participate in the research on Web4Health, and their wishes will be respected.

All clinical research with human subjects will follow the Helsinki declaration.

Additionally, research will be done on people using the Web4Health web site. They will be informed that such research may be done on them.

## **11.3 Privacy**

The privacy of patients will be protected by allowing them to participate anonymously. No attempt will be made to trace the real person behind a pseudonym unless required by law or if this is necessary to stop gross misuse of Web4Health.

No registration of personal information for identified persons will be done without their permission.

## **11.4 Influence on Patients**

The responsible person for the clinical study will ensure that the study will not negatively influence the treatment of the patients.

If use of Web4Health is found to have a negative effect, we will try to correct the problem, and if this does not work, the clinical trials may have to be stopped.

## **11.5 Risk**

### **11.5.1 Risks with our own medical content**

We are aware of the special risks of medical information in the area of mental health. Our web page aims to give advice for common problems but is not designed to replace professional mental health care. Major psychiatric disorders like schizophrenia or aspects of chronic posttraumatic stress disorders / trauma will therefore not be handled in detail. Suicidal thoughts or severe depressive disorders might demand emergency help from a local mental health professional or psychiatric ward. Special care will be taken to avoid any misuse of the system in the area of mentally ill people.

To reduce this risk, we will carefully word our texts in such a way that they will not cause non-constructive negative thoughts. As an example, if we provide a personality test result, which has a scale of assertiveness, we could label low assertiveness with the word “unpretentious” and high assertiveness with the word “decisive”, i.e. using positive words for each alternative. (This is just an example, there is no decision to provide any personality test results by our project.)

We will also clearly specify that people should seek medical or specialist care and not regard our informational pages as any personal treatment recommendation for individual people.

We are developing a separate “Quality plan”, which will cover this in more detail [Piccini 2002].

### **11.5.2 Risks with forums and chats**

The largest risk is with open forums and chats, where anyone can participate and may write unsuitable or illegal things (like recommendations to use narcotics to help with psychological problems). We will monitor the forums and chats and write corrections if necessary, as well as remove illegal or unsuitable content and ban people who misuse the forums from using Web4Health, or change the status of forums where abuse occurs to moderated status, if needed.

## 12 References

- EU1 Guidelines For Quality Criteria For Health Related Websites, [http://europa.eu.int/information\\_society/eeurope/ehealth/quality/draft\\_guidelines/definitions/index\\_en.htm](http://europa.eu.int/information_society/eeurope/ehealth/quality/draft_guidelines/definitions/index_en.htm).
- Palme 1995 Electronic Mail. Artech Books, Boston, London 1995. ISBN: 0-89006-802-X. URL (to more information, not the whole text): <http://dsv.su.se/jpalme/e-mail-book/e-mail-book.html>
- Piccini 2002 Quality Assurance Plan, by Fabio Piccini et al. Forthcoming project report.

## Appendix A: The Web4Health User Registration Page

Here is a draft text for the Web4Health user registration page English. The layout below is not exactly as on the web site, to view the page, go to <http://Web4Health.info/en/personal/>.

# Register in Web4Health Forums and Chats



### Rules for Using the Web4Health Forum Facilities



Web4Health is intended for serious exchange of information and experience on psychological problems. If you want to discuss your own or your friends' and relatives' problems, you can participate pseudonymously (your real name is secret), but you still have to adhere to these rules.



If you are a non-expert, and want to learn about or discuss problems of yourself, your friends or relatives, you are allowed to participate anonymously, using a secret name chosen by you and only known to yourself. Other users must give their real name below.



Be nice and respectful to each other, do not say nasty, threatening and defamatory things.



You may not use Web4Health to say illegal things, such as racial agitation, child pornography, slander, etc. or to write information which is known to be false.



You may not use Web4Health for commercial marketing without permission from the Web4Health maintainers.



Be careful with the user of irony, people will easily believe that you mean what you write. Mark irony with ":-)".

**I accept**

Web4Health reserves the right to remove contributions which are against these policies.

If you do not adhere to these rules, we may cancel your Web4Health account. If you participate pseudonymously, we will try to cancel your account without identifying who you are.

Web4Health reserves the right to remove unsuitable contributions from forums and chats.

You can make a complaint against abuse of Web4Health by writing e-mail to Web4Health-abuse@Web4health.info.

### Registration Form

[i more info](#)

Fill in the form and click on the "Register" button below.  
TIP: Use the TAB button to jump between the fields.

**Your name ( or  
secret name known  
only to yourself for  
people with  
psychological  
problems, their  
relatives and  
friends):**

[i more info](#)

- My real name  
 A secret name

**Choose a short,  
unique login id:**

[i more info](#)

**Your email address  
(not required):  
(if you do not  
specify any  
address, KOM will  
give one to you)**

[i more info](#)

Do not show my e-mail address to other users

**Choose a  
password:**

**Choose a  
password:**

**Male**  **Female**

**(not required)**

**I want mailing list contributions via e-mail.**

**I want a newsletter by e-mail**

**Default for text input:** Plain Text  Smart  HTML

**Command Language:**

**all languages are not fully supported:** [i more info](#)

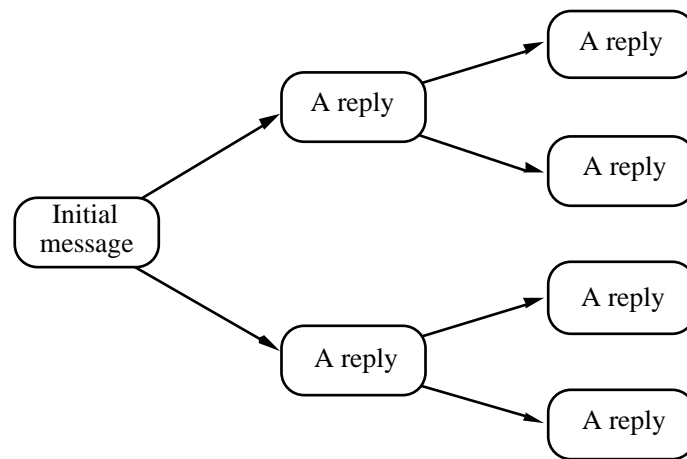
**Personal homepage (not required):**

**Short presentation of yourself (not required):** Plain Text  Smart  HTML

**Test e-mail to yourself (not required):** Plain Text  Smart  HTML   
You have been added as user of "SALUT Forums and Chats" with the login id "foo" and the password "bar".  
You can access KOM through the URL  
<http://salut.nu/forum/uno/>.  
  
You can change your personal settings by clicking  
"Personal" and then "Personal settings".  
  
You can see which forums/mailling lists you are  
subscribed to by clicking "All forums" and then

## Appendix B: Critical Mass Effect

Here is a text describing the "critical mass" effect for forum, the text is a revision of some parts in [Palme 1995]:



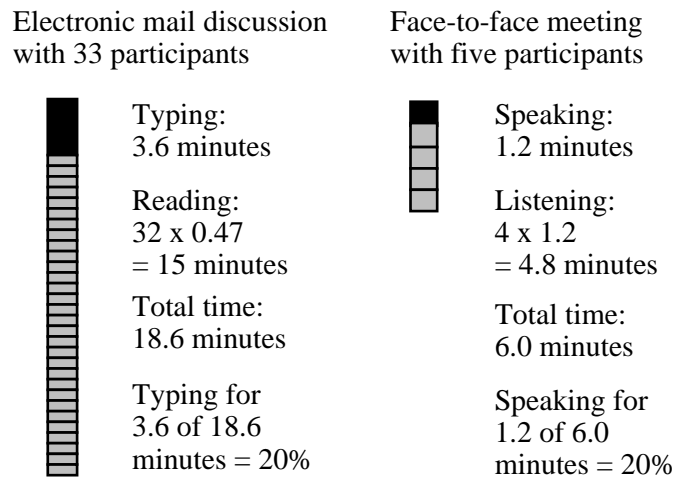
**Figure 1: Chain reaction of group discussions in electronic mail**

Electronic mail commonly uses either distribution lists or forum systems for group communication. The lower size limit for a successful group for the exchange of experience is usually between 20 and 50 active participants. (Groups for other tasks than experience exchange can be successful with much smaller group sizes.) This is probably because the activity in these groups is a kind of chain reaction. Much of what is written is a response to a previous message. Assume, hypothetically, that the probability for each group participant to reply to a message is 0.05. With  $N$  participants in the group, each message will on average generate  $0.05 \times (N-1)$  new messages. If the group size is 21 participants, then this figure will make 1. Thus, with fewer than 21 participants in the group, on average, each message will generate less than 1 new message, so that the chain reaction is sub critical. If the group size is larger than 21 participants, each message will, on average, generate more than one message, and we get a sustained chain reaction. Of course, the real figures are not always exactly 0.05 and 21, but the principle still applies: group size must be above a certain threshold if activity within the group is to be sustained.

Figure 1 shows how a chain reaction of messages can arise if each message on average causes more than one replying message.

An interesting factor to note is that, in a face-to-face meeting with 5 participants, each participant is allowed to talk for an average of 20 percent of the time. In an electronic mail meeting with 33 participants, each participant also spends 20 percent of the time giving information, writing messages, etc. See Figure 2.



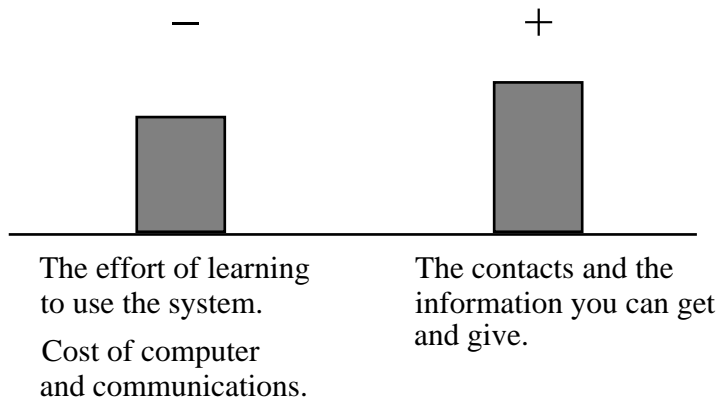


**Figure 2: Number of participants to get roughly  
20 percent giving and 80 percent receiving per participant**

Maybe human communication (with equal speaker rights) works best psychologically if the participants can be active and give information at least 20 percent of the time. This could be the reason why face-to-face meetings seem to be most efficient with group sizes of about 3-7 people, while group communication using electronic mail or computer conferencing systems seems to be efficient in groups of 20-100 people or more.

Few people will obtain a computer just to use electronic mail. *Electronic mail* is usually a fringe benefit of having a computer at your work or home. Many people feel that it is not worth the effort of learning to use a computer just to be able to use electronic mail. If, however, you already have a computer and regularly use it, then it requires little extra effort to use electronic mail. Also, a person who has entered the “wonderful world of computers” often needs to communicate with other people who use computers and electronic mail is a natural medium to use.

Everyone makes a personal choice of whether electronic mail is worth the cost just for him/her (It is seldom successful to try to force electronic mail on people who do not themselves feel the need for it).



**Figure 3: Factors in a personal decision to use or not to use electronic mail**

Figure 3 shows the most important pros and cons in this personal choice. These factors are important, if you want to predict whether the introduction of forum usage in a group will be successful. If the people involved already use computers and if you can make the electronic mail application easy to use, then this will increase the probability of success. If the forum application allows its users to reach many people and if they find it important to exchange information with these people, then the probability of success will again increase. Note that the pros are related to the volume of e-mail usage, while the cons are volume independent. Thus, larger group size increases the likelihood that people will feel that the pros will outweigh the cons.