



CHARTER FOR PATIENTS' DISCUSSION LISTS

(long version - 12 June 2007)



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1. Introduction

This Charter's goal is to propose guidelines to regulate patients' email discussion lists. The Charter specifies the correct rules of community life for this type of exchanges.

The Charter refers to discussion lists involving people concerned with health problems on a purely non-professional basis; professionals can also take part in the debates, insofar as a list's specific rules authorise this.

The objectives of these lists are to:

- provide information
- help patients in the everyday management of their disease
- provide support for patients and those close to them, and end their isolation
- facilitate the sharing of experiences
- and possibly to support the intervention of patients in public spheres (media, scientific and medical circles, public organisations)

The Charter regulates the life of a discussion list while ensuring:

- that the discussions are correctly held, with respect for the speakers and their messages
- subscribers' right to information
- transparency of the exchanges
- confidentiality of the messages and the personal data
- respect for privacy
- protection from advertising, and commercial or other requests
- security of the list's archives

The Charter specifies and delimits the roles of the various participants implicated, for different reasons, in putting on-line, managing, and animating a discussion list.

2. Status of the Charter

This Charter was developed on the basis of the discussions of a working group made up of experts and users. The methodology used and the list of this group's members are to be found in paragraph 9.1.

Eurordis (European Organisation for Rare Diseases) initiated this project thanks to funding from the LEEM (Les Entreprises du Médicament).

This Charter is based on the general principles defined in the Guidelines for Providing Information on Rare Diseases developed and published by Eurordis in 2003 thanks to funding from the European Commission and AFM-Téléthon.

This Charter is not a final document. Validated by Eurordis, it takes into account the working group's remarks and suggestions as of December 31st 2006. Certain subjects may not have been broached; the Charter will evolve as different issues are discussed.

The current document will be publicly disseminated. Available in English and French, it will be published on Eurordis' website (<http://www.eurordis.org>) and will be also sent to the persons in charge of Eurordis member associations.

This document can be used as it stands by any association, and by any person in charge of, or managing, a patients' discussion list; it can also be used by any person who wishes to create a discussion list specifically for patients.

The source of information, Eurordis, and this document's date of publication (December 2006) must imperatively be cited.

Any comment or request must be addressed to eurordis@eurordis.org.

3. Scope of the document

This Charter has no legal value; it commits people on a voluntary basis, just as registration with a list is voluntary.

It does not apply to free access discussion groups of the Usenet type or to discussion forums available exclusively from a Web interface.

The good practice guidelines defined in this Charter are intended for the various participants implicated in patients' discussion lists.

They specify the questions that the persons in charge of these lists should ask themselves and can be used as they stand, or redefined to take into account each list's specificities. This Charter should also be adapted according to national customs.

Each subscriber receives the rules at registration, to enable him to take note of the rules to be respected on a list; in the event of conflict the various participants can therefore refer to them.

When a list's participants cannot reach an agreement, mediation should be undertaken before, if necessary, undertaking legal proceedings.

4. Definitions

4.1. What is a discussion list?

4.1.1. E-mail

An e-mail is a message sent in the form of text, image or sound on a telecommunications network, which is stored on a server, and can be recovered by the recipient.

4.1.2. Discussion list

A discussion list enables a group of people to communicate on a given topic by means of e-mail.

4.2. Characteristics

A discussion list is interactive. When a subscriber posts a message all the other subscribers receive it, and each one can either answer in a personal way to the author of the message, or in an open way to all the members of the list.

It is an asynchronous medium as, in the majority of cases, the response to a message is not immediate. Subscribing to a list is, in general, voluntary. Only the subscribers receive the list's messages.

Patients' discussion lists are defined by a common interest in a pathology, for example rare diseases, or in any health-related issue.

4.3. Operational principles

An automat, a programme that functions permanently on a machine, receives the messages addressed to the lists that it manages. It then retransmits them to the list's subscribers or holds them at their disposal. The automat also manages the registrations and registration cancellations by means of a specific e-mail address reserved for orders (registration, registration cancellation, requests for help...).

4.3.1. Registration and registration cancellation

Participation in a discussion list requires "enrolment" or "registration". This is the most common case, in particular for the lists between patients.

This mode of registration is called "Opt-In", i.e. with obligatory registration: the person wishing to take part must voluntarily set-off his registration.

There are also "Opt-Out" lists, for which the users are automatically registered: a message is sent to them with an option to cancel the registration.

Registration must be free for the subscriber.

4.3.2. Mode of reception of the messages

The discussion lists' software enable each subscriber to personalise the way messages are received. The principal modes of reception are:

➤ Message by message

The messages received on the list's server are forwarded to the subscriber, one by one.

➤ Reception by batch

This mode, called "*digest*" allows the subscriber to receive, at regular intervals, a single message containing all the messages addressed to the list.

➤ Web interface consultation

The messages can be both read, and sent, on-line on an Internet site.

4.4. Terminology

Similar terminology leads to confusion, both among the users, and in the classification by the Internet search tools, which often group various similar expressions such as "discussion letters", " Web discussion forums" and "Usenet discussion forums" in the same category.

It is important not to confuse discussion lists with other similar mediums.

4.4.1. Newsletters

This medium is devoted to one-way dissemination of information or announcements to subscribers. It functions on the same principle as a discussion list, but the subscribers cannot react to the messages that they receive.

4.4.2. Web discussion forums

This type of forum is lodged on a website, and its use requires deliberately connecting to this site. No message arrives directly to the subscribers e-mail.

4.4.3. Usenet discussion forums

These forums use a dedicated system and are based on a different technical structure. They are hosted on the Usenet network and are proposed by Internet access suppliers. This is a completely public medium, most often without any control of the messages.

4.5. Role of the various participants

All these roles can be held concurrently.

4.5.1. Lists' host

A lists' host is the person or entity whose task is to ensure the technical operation of discussion lists. This person has neither an editorial nor a control activity of a list's contents.

4.5.2. Editor

The editor is the person or entity that is the promoter of a list, and is legally responsible for its operation.

4.5.3. List manager

This is a person, or persons, chosen by the editor, or the editor himself. His tasks are to:

- control the contents of the messages addressed to the list
- administratively manage the list and the tools available to the subscribers (blogs, thumbnail portraits...)
- help the subscribers

Only the manager has access to the subscribers' exhaustive data.

4.5.4. Moderator

This is a person, or persons, chosen by the editor, or the editor himself. The moderator's role is to read the messages transmitted to a list and to forward to the subscribers only those messages that he has approved.

In the case of an un-moderated list, there is no moderator.

4.5.5. Subscriber and Author

Any person having registered with a list is a subscriber. As long as he has not posted a message, only the list manager knows that he is a subscriber.

An author is a subscriber who has posted a message on a list.

5. Guiding principles

Patients' discussion lists are a means of communication and interaction between people who freely choose to participate.

This freedom of communication is only by respect for human dignity, for the pluralist character of the opinions, for the law, and for the rules of deontology and medical ethics.

5.1. Respect for individuals, their differences, and their opinions

The rules of non-discrimination entail considering every person as equal and abstaining from any discrimination based on socio-economic conditions, education, religion, sex, way of life, or ethnic or geographical origin. The participants are obliged to respect all cultures and all beliefs.

5.2. Subscribers' information rights

Discussion list subscribers have the right to consult, modify or withdraw their personal data.

5.3. Legal rules

Internet is not a no-man's land. All the laws and directives adopted by the European Union and by the Member States apply to the patients' discussion lists on-line in Europe. These mainly concern freedom of expression, respecting the confidentiality of information and the right to privacy, intellectual property rights, and the protection of young people.

5.3.1. Freedom of communication

In Europe, freedom of communication is based mainly on the European Convention on Human Rights that specifically stipulates, in article 10, that "*Everyone has the right to freedom of expression*".

5.3.2. Respecting the confidentiality of information and privacy

Discussion lists between patients all refer to a health problem.

It is therefore necessary to always respect the confidentiality and anonymity of people's data, unless the persons concerned provide written authorisation.

In addition, all persons who are not doctors, who intervene technically on a list server, and thereby have access to confidential data are held to professional secrecy.

5.3.3. Respecting intellectual property

The texts, images, videos, and sound extracts available on the Internet are subject to royalties, even when they are in free access and no mention is made that they are protected.

Patients' discussion lists must comply with intellectual property laws, both to preserve the author's moral rights as well as to provide proof of the information disseminated to patients.

5.3.4. Protection of young people

The discussions in the patients' lists may concern minors, in particular in the field of rare diseases. Their rights must be respected, in particular as regards their reputation.

5.4. Deontology and medical ethics rules

5.4.1. Respect for medical confidentiality

Medical confidentiality is binding for all health professionals who participate in patients' discussion lists, either by voluntarily registering with a list, or by sporadically participating in the discussion when called upon by list managers.

This "covers everything that came to the doctor's knowledge in the exercise of his profession, i.e. not only what was confided to him, but also what he saw, heard or understood".¹

5.4.2. Help to anyone in danger

This rule applies to all the subscribers of a patients' discussion list, and particularly to those health professionals who subscribe to a patients' discussion list, who identify a situation presenting a threat to the life of a patient, in particular that of a child.

5.4.3. Concept of conflict of interest

A conflict of interest exists in a patients' discussion list when a health professional, or a person in charge of a patient organisation, gives information on a list, and has personal or financial relations with an organisation that could influence his actions.

5.5. Limits of the discussion lists

The essential roles of discussion lists are the exchange of information, and support for patients and those close to them.

They operate under the constraints imposed by respect for people and for the laws.

They cannot answer all questions nor satisfy all subscribers. The essence is that the benefit that they provide be greater than the disadvantages they can generate.

6. Good practice guidelines for list hosts

6.1. Missions of the lists' host

6.1.1. To provide the means

6.1.1.1. Registration and registration cancellation

➤ Conditions of access

Registration should be subject to no other condition of access than that defined by the list's managers.

Owing to the fact that registration concerns patients or those close to them, it should be independent of any obligation to subscribe to other services proposed by the host.

It must be free for the subscriber.

¹ Article R4127-4 of the French Public Health Code
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- Information requested

The information requested at registration can be simply an e-mail address, or include the identity of the candidates. For lists with restricted access, additional information can be requested, for example a telephone number, to confirm the identity of the candidates.

- Registration procedures

At the time of a subscriber's request for registration by e-mail or on the list's website, if this exists, the host must control the sender's address by returning a message to this address, confirming registration, in order to avoid requests for registration by third parties.

He should send an e-mail of confirmation for any registration, specifying the e-mail address from which this registration was carried out.

He can give the subscribers the means to modify their registration e-mail address.

- Registration cancellation

The host provides the technical means necessary for a list's members to cancel their registration.

6.1.1.2. Management of the e-mails

The host of a list is responsible for managing:

- the server (or servers) hosting the lists
- the mail server (or servers)

The host therefore,

- takes part in relaying the subscribers' messages.
- can provide any subscriber, who wishes to remain anonymous as regards the other members of a list, with a pseudonym e-mail address, or at least the possibility of mailing anonymously to the list.

6.1.1.3. Administration of the list

As the data-processing skills of the managers and the subscribers of lists patients' patients may be limited, administration and access means should be simplified.

Each list's host should therefore set-up a web interface, whose sole condition of access should be the authentication of the user.

6.1.1.4. Moderation of the list

- A priori moderation

The managers and/or the moderators can subject the subscribers' contributions to a priori moderation. The host should offer the latter the means to moderate, preferably via a web interface.

- A posteriori moderation

In addition to the contributions already disseminated by e-mail to the subscribers, the host must give the managers and moderators the possibility of removing already archived contributions.

➤ Individual moderation

In certain circumstances, a manager can temporarily wish to moderate just one or some of his list's subscribers, in particular in order to maintain his list's reactivity while restoring a certain serenity to the exchanges between a small group of people not complying with his requests for calm. It is desirable that the host offer this possibility.

6.1.1.5. Technical means

➤ Servers

To ensure the data's preservation the servers that host the lists should be independent from those that back-up the archived data managed by the host.

➤ Means of connection to the Internet

The data transmission capacity (band-width) should be regularly reassessed in case of a significant increase in the flow of messages exchanged.

6.1.1.6. Technical support

The host must provide the managers and editors with technical support in the event of operational problems with the lists:

- e-mails not arriving to their recipients or systematically returned to their sender
- difficulties with access to the list of subscribers
- difficulties with access to archived data
- operational incidents on the list's web page or on the lists' hosting site

The managers should be provided with an e-mail address, to contact the host, specifically intended for the lists' operational problems.

In addition, the host can also create a dedicated list for the managers² of the hosted lists to share their experience and exchange their remarks concerning the problems encountered.

6.1.2. Ensuring availability

The hosting providers are the "persons or entities that ensure, on a free or paying basis, direct and permanent public availability"³ of certain data.

The host is obliged to assure the list's editor that the list of subscribers, as well as the archives, will be preserved on a permanent basis. He must implement and maintain the appropriate data back-up to ensure this.

In the event of the host discontinuing his activity, or the discontinuance of a list, whatever the reason, the host of a site must inform the editor beforehand so that the latter can take all the measures necessary to transfer and safeguard the data.

6.1.3. Safeguarding access to the data

The host is obliged to set-up the technical means necessary to safeguard the access to the data. Only the subscribers can be authorised to access a list, and exceptionally the people authorised by the managers to temporarily participate in the exchanges. The password which finalises the registration process on the list's website should be communicated only after authentication of the person requesting registration.

² In the rest of the document, the term "managers" will be used to refer to the managers and the regulators of a list

³ Article 43-8 of the law of August 1st 2000 (France)
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The host must also reserve access to the list of subscribers solely to the managers.

It is also recommended that the host install anti-virus tools and "anti-Spam" (unsolicited mass mailing of messages to the subscribers).

6.1.4. Technological monitoring

The host should regularly update his knowledge by technological monitoring of the software and data protection tools, in particular to filter viruses and unsolicited e-mails.

6.2. Legal concepts

The following recommendations apply only when the host has a purely technical role, with no editing. The legal responsibilities then come under the hosting system, as it is defined in Directive 2000/31/CE of the European Parliament and the Council of June 8th 2000.

The rules concerning the host must be specified, as it is not always easy to clearly separate the data relating to the contents of the communications from those relating to their identification. Certain technical data, such as the wording of an e-mail, can provide information on the content transmitted.

6.2.1. Conditions of access to information

The host always has the technical capacity to access a list's information, i.e. the e-mails, the list of subscribers, and their identification co-ordinates.

However, the host should only have the right to access the information in the following cases:

➤ **Legal obligation**

The legal system of hosting providers obliges hosts, from the moment that they are aware of the illicit character of stored information, "to act promptly to withdraw these data or to render access to them impossible".

The host can therefore access the data at any time, when obliged by a legal authority or the law to withdraw any illicit text.

The host should also spontaneously take the initiative of withdrawing access to contents which he has been informed are considered illegal.

➤ **Specific request**

The host can access the data on written request from the editor or the managers, when they encounter technical difficulties in accessing these data.

When the editor wishes to access information by using automatic data extraction tools, the host must be consulted to indicate the methods to be used in order to avoid disturbing the site's operation.

The host should not use his possibility of accessing a list's messages to search by key words which would then enable him to post personalised advertising, contextual with these key words, on the list's website.

The host can only use the list of subscribers to inform them of technical problems on the server. Under no circumstances can the host use the list for commercial reasons or to promote products.

If the host were to use this list for other types of messages, he must first inform the subscribers and give them the possibility of refusing them.

6.2.2. Conditions of data consultation

The host is not obliged to supervise the contents of the information that he transmits or stores, nor to identify illicit contents.

6.2.3. Protection of privacy

The messages addressed to the lists and stored by the host contain the users' personal data and private information.

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The host is responsible for the protection of a list's personal data. He must therefore declare the list to the national organisation of the country where the list is hosted, and request an authorisation for processing personal data.

The host must take all measures necessary to ensure the data's protection, in particular by installing dedicated software ("firewalls").

He must also take all measures necessary to render the subscribers' personal data anonymous in the following situations:

- Consultation of the connection data for statistical purposes ("logs"), in order to know the number of connections or the pages most consulted.
The connection data must only be kept during the time necessary for the exploitation of these statistical data.
- Authorisation to access the data presented by the site's editor for computerised requests on the contents of the messages.

Both the relevant national organisations and the subscribers must be informed of these means of protection of people's personal data and privacy.

6.2.4. Professional secrecy

In general, the lists' host is not a health professional looking after one (or several) of a list's patients and is therefore not bound by medical confidentiality.

However, the persons having to intervene on the list's server can be led to peruse contents containing medical information or confidential data.

They are then bound to confidentiality and are thus not authorised to disseminate the data to third parties.

6.2.5. Data preservation

In order to avoid being held responsible in the event of illicit contents being put on line, the host must preserve the data allowing the identification of any person who addressed a message to a list.

6.2.6. Data transfer

Certain hosts specify that archived data can be transferred to another country for storage, for reasons of preservation and safety.

This can also occur in the event of a merger or the acquisition of a private host by another company.

It is specified that the users accept these conditions by submitting information.

The European legislation specifies that the transfer of data to countries outside the European Union is authorised only if the State concerned ensures a sufficient level of protection. Exemptions to this are envisaged. Such a transfer could be considered "when the consent of the person who is the subject of the treatment is obtained or if the transfer is essential for reasons related to the safeguard of life, public interest, the legal defence of a right, the consultation of a public register, the fulfilment of a contract".

During any transfer of data or modification of the host's affiliation, the list's subscribers, managers and editor must be informed beforehand, to allow them to take the measures necessary to withdraw and back-up the information.

6.3. Host – editor agreement

The respective responsibilities are defined in a charter or an agreement signed by both parties. The points included in these texts specify, at least, the technical means proposed, the conditions of data storage, the safety elements set-up to ensure the data's protection and durability, the respect for privacy, and the explanations as to the possible transfer of the information.

6.4. Information to subscribers

A list's editor and/or managers are in charge of informing the subscribers as to the host's responsibilities.

6.5. Limits of responsibility

As long as the lists' host has complied with the rules fixed by the law, he is excluded from responsibility. His responsibility towards the editor is specified in the charter or agreement signed with him.

7. Good practice guidelines for list management

7.1. Definitions: reminder

The editor is the promoter of a list, and is legally responsible for its operation.

The moderator of a list is a person designated by the editor to filter the messages addressed to the list (a priori moderation) by transmitting only those that comply with the rules of good practices defined beforehand.

The manager of a list is a person designated by the editor to supervise that the exchanges go well, to ensure the administrative management, and to provide help to the subscribers regarding the list's operation.

The animators of a list are persons designated by the managers to assist them in the tasks of controlling the messages and helping the subscribers.

7.2. The editor

7.2.1. Identification of the editor

The editor can be a person or an entity.

The editor of a patients' list can be a patient, someone close to patients, or an association concerned with the disease object of the list.

It can also be an association involved with a group of diseases.

A list's subscribers must be informed as to the editor's identity.

When the editor is a doctor, identification by name and function is obligatory.

7.2.2. Editor's functions

7.2.2.1. Designation of the managers

The editor can be the manager of a list, or he can delegate his responsibilities to one or more managers.

7.2.2.2. Limits of intervention

If the editor has delegated his responsibilities, he does not intervene directly in the management of the list, and should respect the managers' independence. It is always possible for the editor to take part in the exchanges by subscribing to the list that he created.

The editor can intervene in the following cases:

- Definition of the subscribers admitted to take part in the lists
- Arbitration of conflicts between the subscribers and the managers, on request of the latter

7.2.2.3. Rights of access to the data

Any request for access to the data (list of the subscribers and archived messages) by persons or entities is subject to the editor's approval. He can only give his agreement after informing the subscribers of the request's object and motivations, and respecting their right to withdraw the data regarding them.

7.2.2.4. Information to the subscribers

The editor is responsible for the information intended for the list's subscribers.

7.2.2.5. Accessibility to the list

The editor should make provisions to facilitate the management of a list by setting-up a web interface.

7.2.2.6. Convention with the host

When the editor does not personally host his list, he should sign an agreement with his host.

7.2.2.7. Replacement of the managers

The editor can ask for a manager to be replaced at any time. This request is transmitted to the host in order for him to modify the list's management rights.

7.3. Management of a list

7.3.1. Identification of the managers

A manager is an individual, not a legal entity.

When the manager is a doctor, identification by name and function is obligatory.

7.3.2. Control of the messages

7.3.2.1. Suppression of a message

The managers have the right to block or remove any message that, according to them, contain any of the following characteristics:

- Political messages
- Racist messages
- Criticism of religious practices
- Sexist messages
- Immoral messages
- Messages that could be against the interests of a minor
- Messages whose contents are illegal in the territory of residence
- Messages containing links to sites whose contents are illegal
- Spreading rumours
- Promoting a treatment without reference to a recognised protocol or a medical publication
- Commercial or advertising messages
- Impolite or rude messages
- Disrespect for intellectual property: not citing the source and the author of any text disseminated in the list
- Proposals of a medical service by one of the subscribers (medical investigation, consultation, registration for a clinical trial)
- Dissemination of private matters of other members of the list, or doctors or nursing personnel
- Messages not complying with the list's rules as defined and freely accepted by the subscriber

- Messages addressed by unregistered persons

7.3.2.2. Selective moderation

The managers are advised to selectively moderate (fine moderation) authors of messages whose contents justified suppression, according to the list detailed above: their messages are then checked by the managers before their dissemination to the list.

The managers should inform a subscriber when he is being selectively moderated, and explain the reasons for this.

7.3.2.3. Exclusion of an subscriber

The managers can exclude a subscriber for the following reasons:

- Repeatedly sending messages whose contents are forbidden on the list
- Abusively repeated or mass mailing of messages ("Spam")
- Registration under several addresses (multiple pseudonyms) on the list, in order to stir-up trouble
- Repeatedly challenging the list's managers
- Constantly disputing the managers' decisions

7.3.3. Administrative management

Only the managers have access to the exhaustive data on the subscribers: list of subscribers, archived messages, and information directly transmitted to managers by subscribers.

7.3.3.1. Registration management

Managers are in charge of checking that subscriber registrations fulfil the selection criteria for participation. They can, at any time, decide to open the list to another category of participants, for example, to doctors.

7.3.3.2. Technical problems

Managers are in charge of alerting subscribers when a message is presented in a way that makes comprehension difficult.

In the event of difficulties with registration or registration cancellation the managers help the subscribers. They should try to solve, with the subscribers, the technical problems generated by invalid e-mail addresses or misuse of their email system, in order to avoid automatic registration cancellation.

7.3.4. Access to the information

The managers have access to the list of subscribers and are bound to secrecy.

They also have access to the traces of each list member's various actions (date of registration, date of acceptance of the good practice guidelines, date of request for registration cancellation...), in order to be able to review each event in the case of dispute.

They have rights of access to the archives of the messages that enable them to remove them.

7.4. Co-management of a list

When a list is under the responsibility of only one manager, he can designate another person, for example a subscriber, to assist him in all his tasks: controlling the messages, solving the technical problems, management and animation of the list.

This subscriber is called a co-manager, and has the same responsibilities and rights as the manager:

The list's editor must validate the designation of a co-manager.

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The co-management of a list requires permanent dialogue between the interested parties, by communication outside the list.

The editor of the list arbitrates any conflict between co-managers.

7.5. List animation

In lists comprising many subscribers and generating a significant number of messages, the managers may find it useful to designate list subscribers to assist them.

These subscribers are called animators. They do not ensure any management tasks and do not have access to the subscribers' list.

These subscribers help the managers with the animation of a list by:

- Proposing new discussion topics
- Pointing out to the subscribers those messages too far away from the sets of themes initially defined for the list
- Ensuring that all messages receive an answer
- Seeking, if necessary, information related to the list's sets of themes for the other subscribers

In the case of lists in which the messages can be written in several languages, it is advisable to nominate animators for each language used in order to draw the managers' attention to those messages that do not comply with the rules defined for the list.

7.6. Information to subscribers

A list's editor provides each new subscriber with information concerning the persons in charge, the desired objectives, the operating mode, as well as the good practice guidelines of the list.

This information is sent at the time of the registration procedure, in the welcome message dispatched by the host, and is validated by the subscriber.

This information should clearly specify:

7.6.1. The host's identity

The name and the co-ordinates of the host should be clearly mentioned.

7.6.2. The editor's identity

A discussion list is a communication tool, and also a source of information. The identity of the people or the organisation behind an Internet information source is a major quality criteria, which also applies to discussion lists.

The reasons for creating the list should also be stated.

7.6.3. The persons admitted to the list

It is necessary to define the categories of patients for whom the list was created: patients, their family, those close to them, healthcare professionals (medical or paramedical), or any person concerned with the subject; and also to specify the public for which access is not authorised, in particular any person wishing to use the list to disseminate commercial information, to obtain lists of e-mail addresses, or to collect funds.

It is also possible to decide that all requests for registration will first be addressed to the managers and should include the motive for registration.

7.6.4. The list's topics

The messages addressed to a list can relate to all the aspects of a disease, or be centred on well-delimited topics, to avoid shocking patients or families confronted with the initial stages of a disease.

In the case of certain rare diseases, the signs only appear in adulthood, and can induce serious behavioural problems, or threaten vital functions.
It can then be desirable to create separate lists with specific topics for each one.

7.6.5. Methods of registration and registration cancellation

They are defined by the editor and installed by the host.

To avoid a rapid registration cancellation, it is advisable to clearly specify, in the welcome message to the subscribers, that various modes of registration are possible, which make it possible to avoid receiving a large number of e-mails in their letter-boxes: either a single message per day recapitulating all the contributions, or direct consultation of the messages on the site hosting the lists.

7.6.6. The language used

The majority of the lists function with exchanges in a single language. Lists concerning a small number of potential subscribers, as for rare diseases, can use several languages in the exchanges.

It is preferable to choose a language of reference common to all the subscribers, so that the messages are accessible to the majority. But those persons who do not know this language should be free to post messages in their own language. It is then necessary to also write the subject of the messages in this language to facilitate their identification.

7.6.7. The managers' role

The managers' responsibilities regarding the control of the messages, the management of the list and the assistance to the subscribers should be clarified in the information message.

The specific e-mail address for contacting the managers should be communicated at registration, and be recalled in each message posted on the list.

7.6.8. The safety of the service and data confidentiality

Subscribers should be informed of the following points:

- The data regarding them are accessible only to the managers and the host
- The access to the archives of the messages is protected
- The subscribers can exert their right of access to the archives, in accordance with the legislation in force in the country, and can obtain, on request, the suppression of the messages of which they are the authors.

7.6.9. Possible participation in studies

Subscribers should be informed of the possibility of studies of the discussion lists' contents.

These requests for participation in surveys or clinical research will be communicated to the subscribers by the managers and subjected to their prior approval.

7.6.10. Good practice guidelines

Their dissemination should be renewed regularly, either periodically by the managers, or at each connection to the list's website before reaching the messages.

The good practice guidelines should also appear on the welcome page of the list's website. If an abbreviated version is sent to the subscriber, the complete version, specific to the list, must be respected in priority.

7.7. Legal responsibilities

All the applicable laws as regards freedom of communication, intellectual property, respect for privacy, protection of the young, and of commercial property, apply to the discussion lists.

The editor is legally and criminally responsible for the contents of the messages posted on the lists, as are the list's host and the author of the message. The editor must therefore ensure that any illicit content be withdrawn at the request of a legal authority.

The editor's delegation of responsibility to the managers has no legal value.

A list's Charter, communicated to the subscriber at registration, should define the rights and the responsibilities of the various participants in the list.

It is useful to revise it regularly in order to encompass circumstances not initially envisaged.

7.8. Participation of doctors, other health professionals, and scientific researchers

Each patients' discussion list defines beforehand the public for which it was created. It also specifies those for whom access is not authorised.

The list's managers are in charge of ensuring compliance with this rule. They can decide, at any time, to restrict or broaden access to the list.

When the list is open to the participation of doctors, they must obligatorily be identified, by name and function, if they give medical information.⁴

When the list concerns a rare disease or a group of rare diseases, managers are advised not to accept the participation of health professionals, and particularly not that of doctors specialised in these diseases. As the number of specialised centres in this field is limited, the doctors could encounter patients in a private discussion area, outside the clinical context, whom they could have to treat. The participation of this category of professionals could modify their relation with the patients and would be also considered interference in their private lives.

However, managers can request the specific participation of specialists, for a limited time, depending on the information needs of the list's members.

It is desirable that these specialists belong to multidisciplinary hospital teams recognised in their speciality, in particular by their scientific publications on the disease, so that they do not express themselves on subjects outside their area of competence. This is especially recommended in the case of rare diseases, an area which requires specific knowledge.

In addition, their interventions should always rest on scientifically validated data, consensually accepted by their peers. The references of these data should be provided. When giving information whose validity is not as yet unanimously recognised, specialists should clarify that they are expressing their personal point of view, or referring to data from studies in progress, and that other opinions can exist.

Potential conflicts of interest should be clearly stated. For example, when these specialists are led to give information about a treatment, and if they collaborate, in whatever capacity, with a pharmaceutical laboratory marketing this treatment, or with private or public institutions involved in the patenting of research on the disease of interest to the list.

Managers are advised to point-out that "the information disseminated on their lists by doctors is valid only at the time when it is emitted and that, due to the evolution of medical knowledge, it can be challenged thereafter".

We also remind you that (cf. 8.2.1.) "The objective of any message posted to a list is purely informative, and can in no way be taken as a medical opinion".

If a doctor subscribed to a list identifies situations which seem to him to present a danger to the health of another subscriber, particularly a vulnerable person, he should intervene to advise the subscriber to consult a doctor, if possible in a structure specialised in multi-disciplinary care, such as a centre of reference, when one exists for the disease concerned.

When these situations are caused by a subscriber's messages, the doctor should warn their author on the basis of objective arguments.

⁴ Report of the French National Council of the Order of Doctors (Dr. Chassort October 2000)

<http://www.web.ordre.medecin.fr/rapport/principesgenerauxexercicesurleweb.pdf>

Such interventions are only justified in the case of exceptionally complex and serious situations.

7.9. Participation of other health world professionals

Managers can request the participation of other health world professionals (lawyers, economists, journalists, manufacturers...), because of their skills in the field. Participation should be for a limited time, depending on the information needs of the members of the list, and these experts' potential conflicts of interest should be stated beforehand.

These experts are also obliged to respect the Charter, and in particular the ethical and legal aspects which apply to them.

7.10. Participation and protection of minors

Certain lists can be open to minors.

When a list is specifically intended for children or for teenagers, who wish to communicate without the presence of adults, the list's information page should specify that adults are not authorised to participate. The participation of adults in these lists, when proven, must lead to their exclusion.

The age limit for the participation of minors in these lists should be indicated, and parental agreement, or that of the legal guardian, requested.

This agreement is also necessary when a minor who is a subscriber wishes to give his name.

If a minor puts himself at risk, the manager must point this out to his parents or legal guardians.

The e-mail address of minors must be rendered anonymous, and not contain the subscriber's name.

The host can provide any subscriber, who wishes to preserve his anonymity as regards the other members of a list, with a pseudonym e-mail address (cf. 6.1.1.2).

Subscribers, and particularly minors, should not communicate their telephone number or their address on a list.

When a minor becomes aware of a message concerning him on a list, he has the right to ask the manager to remove it, without it being necessary to obtain parental agreement, or that of the legal guardian.

Any message that could be contrary to the interests of a minor, or to accepted standards of behaviour, must be withdrawn.

7.11. Messages outside a list

Messages can be exchanged between the subscribers outside a discussion list. These messages are neither the responsibility of the list's editor nor that of the managers; therefore they do not have to intervene.

However, subscribers should be warned against messages wherein a member of a list gives a medical opinion, disparages a treatment, or delivers therapeutic advice.

The warning should be posted on the list's website. In addition, managers can disseminate this warning at regular intervals on the list, specifying that unqualified medical opinions can be dangerous.

7.12. Ownership of messages

A message is an original work that is protected, as such, by intellectual property laws.

Each message belongs to its author, who is responsible for its contents. In no case do the editor and the managers have a right of exploitation of the messages.

The host can have access to them when legally necessary, or at the request of the editor or the managers.

7.13. Access to information

The information transmitted to the subscribers when they register for a patients' discussion list should clearly specify whether the managers accept the possibility of an access to the archived data for computerised requests regarding the contents of the messages.

If they do, requests for access should not be transmitted directly to the subscribers, but addressed first to the managers who decide whether to grant or refuse the request.

If search engines or other automatic data extraction tools are used, the host must first be consulted so as to indicate the methods which make it possible to carry out the operation without disrupting use of the site.

7.13.1. Mailing lists

The host and the managers can use a list's e-mail addresses to send messages relating to technical problems on the server, or to communicate general information, to the subscribers.

Under no circumstances can they use them to disseminate commercial or advertising information.

The exploitation of a list's addresses by external operators wishing to use the list of subscribers to constitute a targeted mailing list for advertising, promotion, or for commercial surveys, must be prohibited.

This regards in particular proposals of medical services.

7.13.2. Requests for funding

The examination of a dossier, for example for the funding of a project presented by the list's editor or host, may imply a request for access to the subscribers' personal information. Even if this request specifically stipulates that the information will not be used for any other goal than to examine the funding dossier, access to the data must not be allowed.

7.13.3. Investigation of discussion lists

The contents of the messages posted on lists can be of interest to researchers who wish to study the exchanges' socio-cultural context, the motivations of the lists' participants, and their reactions to the various modes of care adopted by the doctors. Registration of researchers with lists in order to observe, and undertake a "passive" analysis of the behaviour of a list's members from the contents of discussions - without active participation - makes it possible to better understand how this mode of communication and interaction works, for the benefit of the patients themselves.

The list's managers should be informed as to the registration of researchers, journalists, or other people interested in this approach.

7.13.4. Medical research

The messages addressed to a list represent information liable to be of particular interest to researchers in the medical field. The reactions of patients to their treatments, the side effects and circumstances of their appearance as well as their intensity, adherence to the prescriptions, as well as all the information that is not always brought to the attention of the doctors, constitute a database from which information can be extracted.

Access to the data can be regarded as a contribution by the patients to biomedical research.

The list's members should be clearly informed of any request for access to the archived data for a medical publication. The elements mentioned should include:

- reasons for the study
- detailed information as to the subject of the research
- expected objectives
- researchers' identities and that of their organisation
- use the research results will be put to

- benefit for the members of the list
- other hosted lists also forming part of this study
- precautions taken to ensure the anonymity of the participants
- written guarantees that the anonymous personal data will be only analysed with the subscribers' agreement
- written guarantees that no element enabling the identification of subscribers or people quoted in the list will appear in the publications
- identity of the people to contact for additional information
- mention of compliance with the laws in force in the country where the study will be carried out

The members who do not wish their information to be communicated can ask for their messages to be withdrawn from the list's archives.

7.13.5. Clinical trials' recruitment

Recruiting patients for clinical trials on a patients' discussion list is not advisable. List managers should not transmit proposals for participation in clinical trials, emanating from doctors or promoters, to the subscribers.

However, subscribers to a patients' discussion list can be provided with validated, free of conflict of interest, information about a clinical trial.

In this case, managers have to either provide subscribers with exhaustive information about the recruitment conditions of clinical trial patients, as well as about the potential and emotional risks, or advise them to consult the websites officially in charge of providing this information.

It is not uncommon for list subscribers to discuss the therapeutic tests in which they are, or are considering, taking part. Although these discussions definitely belong on the lists, in view of the, by definition, experimental nature of these treatments, managers should pay particular attention that the discussions go no further than sharing personal experience. In particular, they should warn subscribers as to pronounced opinions, whether positive or adverse, concerning these treatments.

A discussion list between patients participating in a given clinical trial is possible.

8. Good practice guidelines for subscribers

8.1. Drafting messages

8.1.1. Respecting other users

From the moment when a new subscriber's registration is effective, the subscriber can consult any contribution appearing in the files; it is even recommended (though by no means obligatory) that the subscriber consult the subjects most recently discussed on the list.

8.1.1.1. Introducing oneself

When sending their first message to a list, all new subscribers should introduce themselves, by providing at least their first name or pseudonym.

8.1.1.2. Remaining polite

Obviously, it is important to begin a message with a polite greeting. Exchanges between people of different cultures, education, or character can generate disagreements, and can sometimes even appear curt and irritate some subscribers.

Remaining polite and keeping a measured tone in all messages are essential rules. This advice is also valid for all messages addressed to the lists' managers.

Rereading a message before sending it, and modifying or removing certain terms that could be wrongly interpreted, reduces the risk of conflict. In the event of tension on a list it is particularly important to take the time to think before sending a message.

8.1.1.3. Respecting differences

➤ Religion

A discussion list often involves individuals of different religious beliefs.

Faith can provide moral help, and subscribers can mention their religious affiliation; but exchanges must be undertaken in the strictest respect for the beliefs of others. The lists should not be used to proselytise for one's own beliefs, and even less to proselytise for a sect.

➤ Opinions

The lists are not a means to relay opinions. Politics is a very sensitive subject and only information regarding laws or regulations concerning patients can be disseminated on lists.

Managers ensure that subscribers' comments do not question the authorities that promulgated these laws or regulations.

➤ Culture

Lists have members in many countries; this is why references to local cultures should also provide some explanations.

➤ Race

Managers must block or remove any message containing racist terms or insults.

➤ Sex

Managers must block or remove any message containing sexist terms or insults.

➤ Lifestyle

Managers must block or remove any message containing discriminatory terms with regard to lifestyles, sexual orientation, drug abuse, etc...

8.1.1.4. Not spreading rumours

Only information of which one is sure should be disseminated on a list.

This therefore excludes any kind of rumour, for example about a hospital unit or a doctor.

Any announcement about the results of a clinical trial or the possible marketing of a drug is premature as long as the information is not public.

If, for example, a subscriber posts a message on side effects that are not included in a treatment's instructions leaflet, he should take care to specify that this is only his personal case.

"Chain" letters are another way of spreading rumours.

It is important to at least check whether the "urgent" message that one wishes to post to the list is included in the list of identified rumours on reliable sites specialised in the field of misinformation.

If it still seems useful to disseminate such a message to a list, it is preferable to inform the managers beforehand.

8.1.1.5. Avoiding any harassment

Abusively repeated or mass mailing of messages ("Spam") to subscribers constitutes a form of harassment and should not be tolerated.

8.1.2. Respecting laws and regulations

Internet is a network that covers the whole world. Discussion lists are subject to the legislation of the country from which a message is sent or in which the content is read.

The information transmitted in a message is the responsibility of the person who sent it. All subscribers must therefore conform to the laws in force in their country, in particular concerning law and order, intellectual property, and respect for the privacy of other patients as well as the nursing personnel.

8.1.2.1. Law and order

It is advisable to exclude from all lists any subscriber who posts messages contrary to law and order or containing subjects that infringe morality.

8.1.2.2. Privacy

All subscribers should only express themselves in their own name or on behalf of their sick child.

It is illegal to use a message to disseminate elements concerning the private lives of other members of the list, or of doctors or nursing personnel.

For example, it is recommended not to indicate the personal addresses, emails and telephone numbers of doctors; only their professional contact details can be transmitted to a list.

Before mentioning facts concerning an adult, it is necessary to obtain permission, preferably in writing. This is particularly the case for information collected privately, outside the list.

8.1.2.3. Intellectual property

Any information disseminated on a list must respect royalty and copyright laws. When the contents of a document are quoted in a message, the name of the author and the source of information must be cited.

This concerns, in particular, scientific publications, the summaries published in databases such as Medline, or statistics regarding treatments.

8.1.3. Respecting the list's discipline

8.1.3.1. Questioning managers

Managers are charged, in particular, with ensuring the list's discipline. For the list to function correctly it is essential to respect their decisions, not question their motives, and not reproach them for the behaviour of other members.

8.1.3.2. Reopening closed discussions

Sometimes a manager decides to end a discussion; for example, when the exchanges no longer advance the debate and do not bring anything new to the subject. It is then necessary to conform to the manager's decision.

8.1.3.3. Mystification

Certain subscribers sometimes register with one or even several lists under multiple pseudonyms, which can contribute to clouding the exchanges.

When these subscribers do not respond to a request for justification on behalf of the managers, they can be excluded for mystification.

8.1.3.4. Limits between information and publicity

Information messages regarding the existence of other discussion lists concerning the same pathologies are possible; but it is desirable that the managers be personally informed before the rest of the list.

They should not be followed by systematic reminders encouraging the subscribers to join these lists.

8.1.4. The subject of the messages

8.1.4.1. A precise subject related to the message

To allow the subscribers to quickly identify the topic of a message, the subject field must be as precise as possible, as this is the text that first appears when a mailbox is opened. This also facilitates the archiving of the old messages.

In the case of multilingual lists, the subject makes it possible to identify the language of the messages.

Care must be taken to ensure that the subject is truly related to the text of the message.

Lists can agree to "flag" certain recurring sets of themes before the subject of the messages.

In this case, the managers should regularly post a message explaining the significance of the flags used.

8.1.4.2. A new subject for a new discussion thread

A discussion thread consists of a series of answers to a same initial message, which preserve the subject and thus facilitate the classification of the messages.

If the subject of the discussion differs from the initial debate, it is preferable to initiate a new discussion thread while avoiding using the "reply" function, and by posting the new message to the address of the discussion list.

8.1.4.3. One subject per message

To facilitate the follow-up of the answers, it is advisable to avoid broaching several different subjects in one message.

To answer a message that contains several different subjects it is preferable to post separate messages, each responding to an element of the initial text.

8.1.4.4. Messages outside the subject

Messages that are clearly unrelated to the sets of themes initially defined for a list should be avoided.

If in exceptional circumstances they are sent, it is possible to introduce the beacon [NOISE] into the subject to make it possible for the other subscribers to filter them.

8.1.4.5. No accents, cedillas, or special characters in the subjects

Subscribers to the lists use different mailbox software whose coding systems are often incompatible.

It is therefore preferable to avoid using accents on letters, C cedilla (specific to French), or any other special characters, and to only use the characters of the international alphabet, common to most countries, in the subject.

8.1.5. The body of the messages

8.1.5.1. Contents in rough text

When sending a message, the mailbox software generally proposes choosing between HTML or text format. It is advisable to choose text format, as HTML can carry viruses or deteriorate the contents of the messages of a discussion thread.

8.1.5.2. Answers after the quoted text

In personal exchanges of mail (outside lists or groups), it can be useful to place the answer before the initial text quoted to accelerate reading. However, in discussion lists, it is preferable to write after the text quoted so the successive contributions can be easily read.

This is not the choice of all lists as some recommend the opposite, in particular in North America.

Email software, such as Outlook Express, require this function parameter to be set beforehand.

8.1.5.3. Quoting only what is necessary for the answer

In the response to a message it is advisable to only include the useful quotes of the original text, and not the whole text, in order to ensure better legibility.

This precaution is even more justified for the subscribers who chose the "Digest" (summarised) format, which makes it possible to receive a single daily message comprising all the messages exchanged during 24 hours. The quotation of the complete text of the messages would make these summaries illegible.

8.1.6. Norms for drafting the messages

The use of capital letters is not advisable, as writing in capital letters in a message amounts to shouting. It is preferable to use asterisks to emphasise a word or an expression. All initials should be clarified.

8.1.7. Signature of the message

All messages must be signed to identify their source; the signature should include at least the first name or pseudonym and the e-mail address, and should not exceed four lines.

It is desirable that the sender of the message mentions, with his signature, his relation with the disease, in order to facilitate reading and to avoid any misunderstanding.

Automatic signatures associated with an attached file should not be used, as they are not posted by certain list management software, or can be rejected by discussion list servers.

8.1.8. Attached files

Sending attached files is generally not authorised on the lists for three reasons:

- It requires all the subscribers having compatible versions of the software used to create the document, for example Word.
- The files can transfer viruses.
- The files overload the servers, as the number of subscribers multiplies the transfer of the same file.

It is preferable to use shared space, generally available on lists, to post documents, texts, images or videos, for fellow list members.

8.1.9. Sending the same message to several lists

Before simultaneously sending the same message to several lists ("cross-posting"), it is advisable to inform the subscribers and to make sure that the subject is truly related to these lists' topics of discussion.

8.1.10. The tone of the messages

In certain circumstances, humour is out of place, as are sarcastic remarks. Sometimes it is hard to tell that a text is not to be taken literally. "Smiley" symbols can cancel the possibly wounding nature of a message.

8.2. Contents of the messages

8.2.1. Informative contents and not a medical opinion

All messages posted to a patients' discussion list can only have an informative goal, and can in no event be taken as a medical opinion; All information relative to a treatment or a diagnosis must be treated with reserve; only a doctor is entitled to confirm the validity of such information.

The information posted on a list by patients is often partial, and relates to only one aspect of their disease. Their history is not always specified. Specifying in a message that the information concerns one's own case, and is not advice, must be the rule.

It is essential that any list's subscribers be informed, at registration, that the purpose of the messages diffused by the members, even if they are patients "expert" in their disease, or doctors, is not to delay or replace the opinion of a patient's medical practitioner.

8.2.2. Respect for the other subscribers' treatments

Each participant in a list must respect the other subscribers' treatment choices.

A subscriber can mention the names of medical practitioners, and the name of the hospitals where they practise.

When he gives a "personal" opinion on their quality, this is his sole responsibility.

In the case of rare diseases, it is advisable to quote multi-disciplinary teams and/or centres of reference.

However, a specific doctor or team of doctors should never be cited as the only ones proposing effective treatments.

8.2.3. No promotion for a particular treatment

Treatment can only be dispensed individually, by a doctor, and depends on each particular case.

One should therefore never indicate that a specific treatment is the only effective one for a disease, even if this was the case in one's own situation.

It is advisable to be prudent when expressing oneself about products that were not evaluated for the disease relevant the list.

It is dangerous to promote doubtful products with supposedly miraculous virtues.

As far as possible the commercial names of drugs should not be given, as they can vary from one country to another. It is preferable to use the name of the active molecule or the ITD (International Trade Description).

8.2.4. Confidentiality of personal information

Before posting a message, each subscriber should be aware that he is sending confidential information, which will be linked to his personal identifiers, to all the participants of his list; he can decide either to maintain anonymity and even register under a pseudonymic address, or to reveal personal information on the list.

This information will be made available of tens, even hundreds of people, whose identity and motivations are most often unknown.

A discussion list is an area of exchange, and not a group of friends.

This is why it is important to be careful when disseminating information to a list when it is personal or related to the private lives of relatives, in particular one's children.

In addition, every subscriber should be aware that part of his own messages could be included in the answers of the other subscribers to the list.

The messages of a list are archived. The site's host of course, protects the archives. It is possible to exert one's right of access to information and obtain the suppression of one's own messages.

However it will be practically impossible to erase the messages emanating from other subscribers that include extracts from them.

All subscribers are therefore advised to carefully weigh the potential benefit of participation in a list against the risks that this comprises for the confidentiality of the information.

It is also advisable to regularly refer to the list's good practice guidelines concerning the protection of privacy.

8.2.5. No form of publicity in the messages

The discussion lists are liable to be hosted by commercial sites, in exchange for posting advertising on their welcome page. This can be tolerated.

However, no form of publicity should appear inside a list nor in the messages, in particular for treatments, clinical trials, doctors, care establishments or health organisations.

The limit between publicity and information is sometimes unclear: in the messages, only links towards personal pages or pages proving real information can be allowed, as long as they are relevant, and not a form of covert publicity.

8.3. Messages outside a list

Usually people respond to all of the list's subscribers. However, exchanges sometimes continue, in private, between two people.

If these are of interest to the group, and always with the agreement of both authors, a summary can be posted for all the members.

If a disagreement arises between the list's managers and subscribers, or between two subscribers, for example for non-observance of the good practices guidelines, the problem should preferably be solved in private and not directly in the list.

The messages outside a list, exchanged between subscribers, are not the responsibility of the editor of a list or that of the managers, who therefore do not have to intervene in these.

However, when a member of a list gives a medical opinion, disparages a treatment, or delivers treatment advice, the subscribers should maintain a critical spirit towards this type of message, as these opinions can be dangerous, especially when they come from subscribers who are not doctors.

8.4. Subscribers' rights

8.4.1. Information to the subscribers at registration

On registering with a list each new subscriber should receive a series of information concerning the persons in charge, the aims, the operating mode, as well as the list's good practice guidelines.

This information, that the subscriber must validate, should at least specify:

- The host's identity
- The editor's identity
- The managers' e-mail addresses
- The type of public admitted to the list
- The list's sets of themes
- The methods to cancel registration

- The possibility of receiving a single message per day recapitulating all the contributions
- The possibility for the subscriber to exert his right of access to the archives and to obtain, on request, the correction or suppression of the messages of which he is the author
- The list's good practice guidelines

8.4.2. Access to the archived messages

Each message belongs to its author, who is responsible for its contents.

The subscriber can ask the managers of a list to suppress messages posted in his own name. However, this suppression will only relate to the list's central archives, as the managers cannot modify the files preserved by the subscribers.

8.4.3. Personal data protection

The list of the subscribers and their personal information must be safeguarded by cryptology means set-up by the host, and rendered anonymous, in particular in the event of access to this information by third parties.

8.4.4. Requests for the subscribers' list for a study or survey

The subscribers must be informed by the managers of any request for participation in surveys or clinical research. Every subscriber has the right to refuse to participate in these studies or surveys.

8.5. Subscribers' responsibilities

The messages addressed by a subscriber to a list can engage his civil liability, in particular in the event of slander or of insult, and his penal responsibility, in particular in the event of racial or religious discrimination, remarks contrary to law and order or to morality, or any impingement of people's privacy.

The managers of a list can decide to withdraw any illicit message, or to exclude any subscriber responsible for it.

The host must remove, at any time, any illicit text when constrained to do so by a legal authority or the law.

8.6. Information to doctors subscribed to a list

When a list is opened to the participation of the doctors, they are obliged to identify themselves, by their name and their function, if they give medical information.

In this case, their interventions should always rest on data that is scientifically validated and consensually accepted by their peers. These data's references should be cited. When specialists give information whose validity has not yet been unanimously recognised, they must specify that they are giving their personal point of view or are referring to data of studies in progress, and that other opinions can exist.

Potential conflicts of interest should be clearly declared. For example, when these specialists are led to give information about a treatment, and if they collaborate, whatever their role, with a pharmaceutical laboratory marketing this treatment, or with private or public institutions implied in the patenting of research on the disease object of the list.

If a doctor subscribed to a list identifies situations that seem to him to present a danger to the health of another subscriber, and particularly that of a vulnerable person, he should intervene to suggest consulting a doctor, if possible in a structure specialised in multi-disciplinary care, such as a centre of reference, when one exists for the disease concerned.

When these situations are caused by a subscriber's messages, the doctor should warn their author on the basis of objective arguments.

These interventions are justified only in exceptionally complex and grave situations.

9. Appendix

9.1. Methodology

9.1.1. Research of available documents on the subject

The majority of the sites hosting discussion lists propose good practice guidelines or "netiquette", which in general do not refer to discussions between patients.

Some sites are specialised in patients' lists and provide more specific guidelines for this field.

On Acor (www.acor.org), Medicalistes (www.medicalistes.org), Braintalk (www.braintalk.org) or Pedtalk (www.pcc.com/lists/pedtalk), in particular, the information available on this subject is dispersed throughout the site, vague, and incomplete.

A systematic search of the medical literature was carried out. In particular the medical reviews specialised in the Internet were consulted, such as the Journal of Medical Internet Research (www.jmir.org) or the Journal of the American Medical Informatics Association (www.jamia.org).

No reference text on good practice guidelines for patients' discussion lists was identified.

9.1.2. Constitution of the working groups

- A main working group was formed with specialists in discussion lists who had published on the subject and with managers of patients' lists. It includes:

Dr. Cyril Quémeras, president of Médicalistes, who devoted his medical thesis to the discussion lists

Dr. Fred Senis, creator of the discussion forum fr.bio.medecine, who devoted his medical thesis to discussion forums

Madeleine Akrich, Cecile Méadel, researchers at the Ecole des Mines de Paris, whose research topics include patients' discussion lists

List managers of the Médicalistes site: Sarah Schneider, Babeth Becker, Jacques Fournet-Fayard, Karine Roumache, Nathalie Trannois, and Cyril Duveau

Lise Daoust, manager of patients' discussion lists in Canada

David Oziel, medical information management consultant, coordinates the group.

- A specific working group was set-up to discuss medical ethics aspects raised by the discussion lists:

Dr. Grégoire Moutel, Laboratory of medical ethics and forensic medicine, Faculté Biomédicale des Saint-Pères, Paris

Dr. Nathalie Duchange, Laboratory of medical ethics and forensic medicine, Faculté Biomédicale des Saint-Pères, Paris

Françoise Reboul-Salze, Department of Information and Communication, Inserm and Mission Inserm-Associations

- At the end of 2005, a legal expert was solicited to advise the working group on the legal aspects of the discussion lists

Benoît Tabaka, Forum of Internet rights

9.1.3. Discussions of the main working group

A document summarising the main points identified on sites specialised in patients' discussion lists, and in the specialised literature, was submitted to the working group. Each general set of themes broached (form of the messages, contents, information to the subscribers, conditions of registration with the lists, participation of health professionals, access to the data...) was subdivided into specific discussion subjects.

A private discussion list, specifically for the working group's exchanges, was put on-line. An on-line collaborative working tool, a wiki, was installed with a protected access. The working group progressively integrated the original document's evolutions as these were validated.

9.1.4. Re-reading group

The intermediate version of this document (December 2005) was reread by Benoît Thirion, who is in charge of the medical library of the CHU (Medical Teaching Hospital) of Rouen, and the manager of the Biblio-Santé discussion list.

Médicalistes list managers, whose remarks were submitted to the working group before being integrated in the document, reread the final version of this document:

Isabelle Dété, Dr. Anne Frobert, Dr. Marion Lagneau, Monique Neubourg, Giselle Penat, JoHan Salmon.

Nicolette Ponsart, manager of the Eurordis Prader-Willi syndrome list, also reread the document for syntax and spelling corrections.

9.2. Acknowledgements

Eurordis would like to thank the members of the working groups for their participation in the elaboration of this document, the experts consulted for their information and advice, as well as this document's re-readers.

About EURORDIS

The European Organisation for Rare Diseases (EURORDIS) represents more than 300 rare disease organisations in 33 different countries, covering more than 1,000 rare diseases. It is therefore the voice of the 30 million patients affected by rare diseases throughout Europe.

EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe. It is supported by its members and by the French Muscular Dystrophy Association (AFM), the European Commission, and corporate foundations and the health industry. EURORDIS was founded in 1997. Further details concerning EURORDIS and rare diseases are available at: <http://www.eurordis.org>