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# CHARTER FOR PATIENTS' DISCUSSION LISTS

(short version - 12 June 2007)

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*This is the abbreviated version of the Charter; for more information please refer to the complete version.*

This Charter proposes the general principles that regulate patients' e-mail discussion lists. It delimits the roles of the various participants implicated in the life of these lists and specifies the correct rules of community life for this type of exchanges.

The objectives of patients' discussion lists are to provide information, to help patients in the everyday management of their disease, to provide support for patients and those close to them, to break their isolation, to share experiences, and possibly to support the intervention of patients in the public domain (media, scientific and medical circles, public organisations).

This document can be used as it stands by any association, and 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.

These rules can also be redefined to take into account the specificities of each list, or be adapted according to national customs.

Each subscriber receives these rules on registration; the various participants can therefore refer to them in the event of conflict.

### **The various participants**

The editor of a list is responsible for it, including from a legal point of view.

The editor can take on the technical operation or entrust it to a host. He can also ensure the administrative management of the list or delegate it to managers or moderators.

The moderator and the manager can exert their right of control on the messages before or after their distribution to the subscribers.

## **1. The guiding principles**

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.

The national laws that apply are those of the list's editor country and that of the host.

This mainly concerns:

- freedom of expression and of communication
- respecting the confidentiality of the information and privacy
- respecting the authors' intellectual property rights
- the protection of young people

### **Respecting individuals, their differences and their opinions**

The rules of non-discrimination must lead to considering each individual equally and to 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.

### **Deontology and medical ethics rules**

- Medical confidentiality  
This binds all the health professionals who take part in patients' discussion lists, either by voluntarily registering with a list, or by sporadically participating in the discussions on the request of a manager<sup>1</sup>.  
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".

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<sup>1</sup> In the rest of the document, the term "managers" will be used to refer to a list's managers and moderators

- **Help to anyone in danger**  
This 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 danger to the life of a patient, in particular that of a child.
- **Conflict of interest**  
It exists in a patients' discussion list when a member of the list, in particular a health professional or a person in charge of a patient organisation, is led to give information on a list, and has personal or financial relations with an organisation that could influence his actions.

## **2. The hosts**

The host is responsible for the management of the servers that host the lists and ensure the reception and the sending of the e-mails.

He defines the registration procedure, which must be free of charge for the subscriber, and provides the means for registration and the cancellation of registration.

He sets-up the technical means necessary for secure access to the data and to safeguard the archives.

In the event of the host terminating his activity, or the discontinuance of a list, the host will inform the editor beforehand in order to enable him to take all necessary measurements to transfer and safeguard the data.

The respective responsibilities of the host and the editor are defined in a charter or a convention signed by both parties.

### **Access to information**

The host always has the technical possibility to access the messages, the list of subscribers, and their identification co-ordinates.

However, he should only access these to solve technical problems on the request of the editor or the managers, or to withdraw an illicit text, on the request of a legal authority.

### **Monitoring the exchanges**

The host does not have any obligation to supervise the contents of the information that he transmits or stores, in particular to identify illicit contents.

### **Protection of privacy**

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. He must also take all measures to ensure the protection of the data and to render personal information anonymous.

### **Data transfer**

The subscribers, managers and editor of a list must be informed beforehand of any transfer of data or modification of affiliation of the host, to allow them to take the measures necessary to withdraw and safeguard the information.

## **3. The managers**

The editor, the person legally responsible for a list's operation, appoints the managers.

He respects their independence and only intervenes in the management of the list to define the categories of subscribers allowed and to arbitrate conflicts between the subscribers and the managers, on the latter's request. He can at any time ask for a manager to be replaced.

### **Information to the subscribers**

The editor of a list provides each new subscriber with a series of information concerning the identity of the editor and the host, the list's themes and public admitted, the norms for registration or cancellation of registration, the managers' role, the safety of the service and the data's confidentiality.

It must be clearly specified whether the managers accept the possibility of access to the stored data for computerised queries concerning the contents of the messages.

This information is sent at the time of the subscription process, in the welcome message sent by the host, and is validated by the subscriber.

### **Managers' roles**

- Control of the messages  
The managers have the right to refuse or remove any message which, in their view, does not follow the rules of the list, in particular: respect of the individuals, their differences and their opinions, respect of the laws, compliance with the rules of deontology and medical ethics, compliance with the rules of the list freely accepted by the subscriber.  
They can exclude a subscriber in the event of misuse, or systematically control his messages before distribution (fine moderation).
- Administrative management  
Only the managers have an access to the exhaustive data on the subscribers. They can also intervene in the event of technical problems identified on the list.

### **Participation of doctors, other health professionals, and scientific researchers**

Each of the patients' discussion lists defines beforehand the public for which it was created. When it is open to the participation of doctors they are obliged to identify themselves, both by name and by occupation, if they provide medical information.

However, the managers can request the specific participation of specialists recognised in their field, for a limited time, which varies according to the information needs of the list's members.

Please remember that "The objective of any message posted to a list is purely informative, and can in no way be taken as a medical opinion".

The doctors must specify whether their interventions rest on scientifically validated data or are still subject to controversy. Potential conflicts of interest should be clearly stated.

The 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 thereafter it can be challenged due to the evolution of medical knowledge".

### **Participation and protection of minors**

Certain lists can be open to minors, and others can be specifically for children or teenagers who wish to communicate without the presence of adults.

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

The age limit for their participation should be present on the list's information page, and parental agreement, or that of the legal guardian, can be required.

If the manager notes that the minor is endangering himself, he must point this out to the parents or legal guardian.

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

### **Access to the information**

When a patients' discussion list accepts the principle of an access to the information stored for computerised queries concerning the contents of the messages, no request must be transmitted directly to the subscribers, but first addressed to the managers to whom it pertains whether to accept or refuse it.

- Mailing lists  
A list's e-mail addresses can only be used for internal information messages and cannot be imparted to commercial operators.
- Requests for funding  
Access to the stored data cannot be granted to support a request for funding presented by the editor of a list.
- Medical or social sciences research  
Access to the stored data can be regarded as a contribution by the patients to scientific research  
The members of a list should be informed regarding any request, including the study's object and its authors, the objectives, the potential benefit for patients, and the means implemented to render the data anonymous.

➤ Clinical trials' recruitment

Recruiting patients for clinical trials on a discussion list is not advisable.

Nevertheless, providing clinical trial information to patients' discussion list subscribers is possible as long as the information has been validated and is devoid of conflict of interest.

When this information is distributed on the list, the managers would have to either provide the 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.

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

#### **4. The subscribers**

##### **Respecting the other subscribers**

Respect for other subscribers implies introducing oneself in one's first message, remaining polite in all exchanges and tolerant of all cultures, all differences and all beliefs.

It is advisable to disseminate on a list only that information of which one is sure and not to relay rumours.

Abusively repeating or massmailing of messages ("Spam") to the subscribers constitutes a form of harassment and should not be tolerated.

##### **Respecting the laws and regulations**

Every subscriber must conform to the laws in force in his country, concerning, in particular, law and order, intellectual property and respect for the privacy of the other patients' members of the list as well as the nursing personnel.

##### **Respecting the list's discipline**

Subscription to a list implies respecting its rules and the remarks of its managers.

Not trying to mystify the managers as to one's real identity and not proselytising for other lists are rules to be respected.

##### **Form of the messages**

➤ The subject of the messages

The subject of a message must be related to the contents and be as precise as possible.

It is advised to treat one subject per message and to modify the subject field when broaching a new topic.

➤ The body of the messages

The use of capital letters is not advisable, since that amounts to shouting.

It is advisable to write after the text quoted to allow good legibility of the successive contributions. It is also advisable to include, in the response to a message, only the useful quotations of the original text, and not its totality, in order to ensure better legibility

➤ The signature of the messages

All messages must be signed in order to identify their source, the signature must include at least the first name, or pseudonym, and the e-mail address.

##### **Contents of the messages**

➤ 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. The purpose of the messages is not to delay or replace the opinion of a patient's medical practitioner.

➤ No promotion in the messages

Treatments can only be dispensed individually by a doctor and depend on each particular case. It should therefore never be stated that a specific treatment is the only effective one for a disease, even if that is the case in one's own situation.

In general, no form of publicity should be associated with the messages inside a list, neither for treatments, nor for clinical trials, doctors, care establishments or health organisations.

- Respect for other subscribers treatment choices  
Each participant in a list must respect the treatment choices of the other subscribers. In particular, a specific doctor, or team of doctors, should never be cited as the only ones proposing effective treatments.
- Confidentiality of personal information  
Before posting a message, each subscriber should be aware that he is addressing confidential information, which will be linked to his personal identifiers, to all the participants of his list. This information will be made available to tens, even of hundreds of people, whose identity and motivations he does not know.  
In addition, a part of his messages could be included in the answers of the other subscribers to the list and could therefore never be erased.  
Every subscriber is 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, particularly in the case of one's child.

### **Messages outside a list**

The messages between subscribers exchanged outside a list are not the responsibility of the editor of a list nor that of the managers, who therefore do not have to intervene in these.

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### 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>