

CHARTER FOR ONLINE COMMUNITIES

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Definitions used in this document

“community”	an online community established by EURORDIS and NORD on the www.rareconnect.org website for the objectives set out under the heading “Introductory” of this document
“healthcare professional”	any person qualified to provide medical or paramedical treatment, support, care or related services within the recognised healthcare systems of either any member state of the European Union or of the United States of America
“member”	anyone registered with a community and entitled thereby to post messages online within the areas specifically provided for that purpose
“minor”	person under the age of 18
“moderators”	volunteer patient representatives
“owner”	EURORDIS and NORD jointly
“the RareConnect team”	the EURORDIS and NORD staff whose email address shall be team@rareconnect.org

Expressions denoting any particular gender shall include the other genders.
Expressions denoting singular number shall include the plural and vice versa.

Introduction

This Charter proposes the general principles that regulate patients’ and caregivers’ interactions in online communities. It determines the limits of the roles of various participants implicated in online community interactions and specifies the correct rules of community life for these types of exchanges.

The objectives of online communities 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, to gather patient generated knowledge on living with the disease and possibly to support the intervention of patients in the public domain (media, scientific and medical circles, public organisations).

Emerging platforms for online collaboration are fundamentally changing the way patients manage their disease. Online communities offer new ways to engage with other patients, caregivers, healthcare professionals, patient support groups and industry. It’s a new model for interaction that can help build stronger, more successful relationships and offer patients quality information on their disease.

This document can be used as it stands by any association, and any person in charge of, or managing, an online community. It can also be used by any person who wishes to create an online community specifically for patients and or caregivers.

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

Each member receives these rules upon registration on the online community website; the various participants can therefore refer to them in the event of conflict.

The various participants

The owner is responsible for a community, including from a legal point of view.

The owner can take on the day-to-day operation of a community and/or partner with a patient organization. He can also ensure the administrative management of a community or delegate it to moderators.

The owner and the moderator can exert their right of control on messages before or after their publishing on the discussion forum or other online area of a community.

1. The guiding principles

Individuals are responsible for all posts they make on online communities. All the laws and directives adopted by the European Union and by the Member States, as well as in the United States of America, apply to online community usage. The national laws that apply are those of the community owner's country and that of the moderators.

This mainly concerns:

- freedom of expression and of communication
- respecting the confidentiality of personal information posted on a community 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, gender, way of life, sexual orientation, or ethnic or geographical origin. Online community members are obliged not to denigrate or abuse the cultures and/or beliefs of others.

Deontology and medical ethics rules

- Medical confidentiality

This binds all the medical professionals who take part in online communities, either by voluntarily registering on a community, or by sporadically participating in the discussions on the request of a moderator.

The principle covers everything that came to the knowledge of such a professional in the exercise of his profession, i.e. not only what was confided to him, but also what he saw, heard or understood.

- Help to anyone in danger

This applies to all the members of online communities, and particularly to those healthcare professionals who join a patient or caregiver focused online community, who identify a situation presenting a danger to the life of a patient, in particular that of a minor.

- Conflict of interest disclosure

If a member of an online community is also a medical professional, a medical researcher, a company representative, or a person in charge of a patient organisation and is giving information in a community, they should disclose any personal or financial relationships with an organisation that could influence their response.

- Involvement of company representatives

Pharmaceutical company representatives or marketing firms contracted by pharmaceutical companies are only allowed on invitation from the patient community and should identify themselves accordingly while following the same marketing restrictions that exist in face to face meetings.

When participating in an online community, company representatives must abide by these guidelines:

If you are from a company and looking for case studies or to interact with patients, please contact the RareConnect team on team@rareconnect.org and do not post or make contact with members directly

No promotion for a treatment or any other product

No proposal of a medical service

No registration or recruitment for a clinical trial

No judgment about research protocols which might be discussed by patients

2. The hosts

The owner is responsible for the management of the servers that host a community and ensures the reception and the publication of posts added to a community.

The owner defines the registration procedure, which must be free of charge for the member, and provide a means for registration and the cancellation of registration.

The owner sets up the technical means necessary for secure access to the data of a community and to maintain and safeguard archives of the same.

In the event of the owner terminating his activity, or the closure of a community, the owner will inform the members beforehand in order to enable them to take all necessary measurements to transfer and safeguard the community's data.

If a community ceases to exist:

1 - Members of the community shall be informed of the closing, for example by means of a post on the site or email message to all active members.

2 - Data (messages, testimonials) shall be kept by the owner for one year.

3 - Data must be anonymised after a year and such data shall thereafter be stored by the owner.

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

The respective responsibilities of the owner and the moderators are defined in a partnership agreement or a convention signed by both parties.

Access to information

The owner shall at all times have the technical means of accessing the messages of a community and its list of members (including, but not limited to, their email addresses).

However, the owner should only access these to solve technical problems at the request of the moderators, or to send the member a message about their account.

Monitoring the exchanges

The owner does not have any obligation to supervise the contents of the information that is posted or stored in the community, in particular to identify illicit contents.

Protection of privacy

The owner is responsible for the protection of a community member's personal data. The owner must therefore declare the online community to the national data protection organisation of the country

where the website 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 members, moderators and patient groups that are a part of a community must be informed beforehand of any transfer of data or modification of affiliation of the owner, to allow them to take the measures necessary safeguard and/or withdraw their information.

3. The moderators

The owner, the person legally responsible for a community's operation, appoints the moderators. He respects their independence and only intervenes in the management of the community to define the categories of members allowed and to arbitrate conflicts between the members and the moderators, on the latter's request. He can at any time ask for a moderator to be replaced.

Information to the members

The owner of a community shall provide each new member with a set of information concerning the identity of the owner and the moderators, the community's themes, the types of members admitted, the norms for registration or cancellation of registration, the moderators' role, the safety of the service, and the confidentiality of data.

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

This information shall be sent to a member at the time of the registration process, in the welcome message emailed by the owner, and the member shall be required to acknowledge and accept it by means of a validation link in the welcome message.

Moderators' roles

- Control of the messages

The moderators have the right to refuse or remove any message which, in their view, does not follow the terms and conditions of the community, in particular: respect for the guiding principles set out in section one above.

They can exclude a member in the event of misuse, or exclude his messages before distribution (pre moderation).

- Administrative management

Only the owner has access to the exhaustive data on the members. They can also intervene in the event of technical problems identified on the community.

Participation of healthcare professionals and scientific researchers

It rests with each community to define the public for which it was created before the community is published online. When that community shall be made open to the participation of healthcare professionals, they are obliged to identify themselves, both by name and by occupation, if they provide medical information.

However, the moderators can request the specific participation of specialists recognised in their field, for a limited time, which shall vary according to the information needs of the community's members.

Any healthcare professional supplying a statement and/or information for quotation in whole or in part within a community must state at the same time whether such statement and/or information rests on scientifically validated data or is still subject to research. Potential conflicts of interest should also be clearly stated. When any medical opinion is provided or quoted within a community, the following

wording must be published with it: "NOTE: The objective of any message posted to a community is purely informative, and can in no way be taken as a medical opinion upon which reliance may be placed".

The moderators are advised to point out that "the information posted on this community by or on behalf of and with the consent of any healthcare professional is valid only at the time when it is emitted, and that thereafter it may be challenged due to the evolution of medical knowledge".

Participation and protection of minors

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

The age limit for participation by minors must be quoted on the registration information page, and parental agreement or that of the legal guardian, for such participation may be required.

If a moderator notices a minor on the community, they should alert the RareConnect team. The RareConnect team will send the minor a Protecting Yourself Online document and shall in the interests of the minor monitor the messages the minor shares on the community.

If the moderator reasonably believes that the minor is endangering himself, he must point this out to the RareConnect team, who shall be responsible for informing the parents or legal guardian.

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

Access to the information

When a community accepts the principle of access to the information stored for computerised queries concerning the contents of the messages, no request may be transmitted directly to the members, but must first be addressed to the moderators to whom it pertains in order for a decision to be made whether to accept or refuse it.

Mailing lists

A list of community members' email addresses may only be used for internal information messages and shall not be imparted to commercial operators.

Requests for funding

Access to the stored data shall not be granted to support a request for funding presented by the owner.

Medical or social sciences research

Access to the stored data may be regarded as a contribution by patients to scientific research. The members of a community must be informed regarding any such access request and be supplied with the following details: the study's objectives and its authors, the potential benefit for patients, and the means implemented to render the data anonymous. The aim of the study should include: improving knowledge of the given disease and/or related and/or consequential conditions, and improving patient quality of life or health.

Clinical trials' recruitment

Recruiting patients for clinical trials on an online community is not advisable. Nevertheless, providing clinical trial information to members is possible as long as the information has been validated and is devoid of conflict of interest.

When this information is distributed on the community, the moderators must either provide the members with exhaustive information about the recruitment conditions of clinical trial patients, as well

as about the potential risks (including those to psychological or emotional health), or advise them to consult the websites officially in charge of providing this information.

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

4. The members

Respecting the other members

Respect for other members 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 that members seek to share information of which they are sure and do not relay rumours.

Abusive repetition or mass mailing of messages ("Spam") to the members constitutes a form of harassment and will not be tolerated.

Respecting the laws and regulations

Every member 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 members of the community as well as for any medical professionals that may take part.

Respecting the community's discipline

Subscription to a community implies respecting its rules and the requests of its moderators. An important rule is that members do not try to mystify the moderators as to their real identity and do not proselytise for other communities.

Form of the messages

Messages may include testimonials, comments on testimonials, forum posts, or forum post responses.

The subject of the messages

The subject of a message must be related to the contents and should be as precise as possible. It is advisable 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 may be construed shouting. 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.

If a moderator makes major meaning change to a forum post, they should declare that they edited the post at the end of the entry.

Contents of the messages

Informative contents and not a medical opinion

All messages posted to an online community can only have an informative goal, and can in no event be taken as a medical opinion. No message may have as its purpose to delay or replace the opinion of any 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 community, neither for treatments, nor for clinical trials, doctors, care establishments or health organisations.

- Respect for other members' treatment choices

Each member must respect the treatment choices of the other members. In particular, a specific doctor, or team of doctors, should never be cited as the only source of effective treatments.

- Confidentiality of personal information

Before posting a message, each member should be aware that he is addressing confidential information, which will be linked to his personal identifiers or chosen username, available to all the registered, signed-in members of the community. Such information will therefore potentially be available to tens, hundreds, or even thousands of people. It is impossible to know the real identity and motivations of all these people and proper precautions should be taken to protect one's own confidentiality and that of others.

Every member is therefore advised to carefully weigh the potential benefit of participation in an online community against the risks that this poses for the confidentiality of personal information, particularly in the case of a minor.

- Photos

Photos of other patients or community members should never be shared without permission

Private Messages

Members have the option to become "friends" with other members of their community and thereby acquire the ability to exchange private messages. Members should use their judgement when deciding whether or not to accept a friend request. Moderators have the ability to send private messages to all members of the community. The private messages between members exchanged outside an online community are not the responsibility of the owner nor that of the moderators, who therefore do not have to intervene in these.