EURORDIS
European Organisation for Rare Diseases

INFORMATION SERVICES FOR RARE DISEASES

A manual to guide their creation and development

Booklet 1

Preparing the group and delivering information

AFM | TÉLÉTHON

European Commission

Objectives

This manual is intended for the creation or the development of information services in the field of rare diseases. It is agreed that no information service can exist or be delivered outside an organisational structure, usually a patient group. It is for that reason that attention is given to establishing a robust organisation that can deliver the service. It does not matter how small or big that organisation is or whether it is run by volunteers or salaried staff. What matters is the quality of information, the access to it, and its appropriate delivery. This manual focuses on these actions. Information services include classical tools (printed materials and brochures, one-to-one counselling, meetings) as well as tools derived from new technologies (Internet websites, virtual forums, electronic documents), and intermediate services (classical and requiring more and more new technologies) such as phone lines, among others. These services may be direct (one-to-one like telephone lines and one-to-many public meetings) or indirect (printed materials, leaflets etc.).

The objectives are to guide the creation or the development of such delivery services, emphasising the main principles, mentioning possible obstacles, and proposing tested solutions, i.e. good practices. They focus on specific requirements and issues related to information on rare diseases, and provide some insights on general recommendations for the management of the service. Technicality is not addressed in great detail.

Information in the field of rare diseases is primarily intended for people who are affected by a rare disease or a rare disability, their families and relatives, and also for a broader audience among health professionals and the general public.

Targeted audience

This manual targets people who would like to create information services about a rare disease with little or no support: isolated patients or parents willing to initiate a local or a national programme, patients' groups that are already structured and active but that do not provide information yet. Institutions, medical departments, social services, or governmental organisations may be considering creating such information services, and resources exist to support such initiatives.
Patients' groups that are already providing information services will benefit from this manual as they can compare their practices with what counterpart organisations have validated elsewhere.

Sources

Principles and examples of practices described in this manual result from a qualitative survey conducted in most European Union countries from March to May 2003. 31 organisations were interviewed about the information programmes they provide, and the results were discussed during the European Workshop of National Alliances, Namur, May 2003.

Format

The booklets are available as electronic files (.pdf) on the Eurordis website and as printed handouts for direct distribution. For more information, visit our website: www.eurordis.org

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1. PREPARATORY ACTIVITIES

SETTING UP THE PATIENT GROUP

Patients with a rare disease, and isolated patients in particular, and their caregivers can gain a lot from an information service: a chance to share experiences, fears, frustrations, anger, and victories. They also want to learn from others who "have been there and done that", to ask questions which they have been afraid to ask their doctor, either through conditioning or fear of sounding silly. They want hope, they want to realise to what extent life continues after a severe diagnosis,

disease is not a death sentence, and contact with peers can greatly contribute. And they (in the case of the caregivers) want to be understood and be involved, as much as the affected patient.
Information services are set up for a number of reasons. In the case of childhood diseases, contact with other parents is the most common wish. Sharing experiences and information is also important, especially when a person has a particular condition or disability.

1.1. What to assess

Prior to starting operations, it is essential to define objectives, target population, disease area, means and resources.
For example, an important issue is whether or not there is an information service or a group already covering this condition. As resources and energies are limited, it may not be necessary to duplicate what others are already doing. Where a group already exists, it is recommended not to set up another. However, you may consider your issues are so specific that you need your own information service. There is no classification of rare diseases, and some groups have decided

to address multiple disorders. For example, an existing service could deliver information on several neurodegenerative disorders, each of them being so complex that the service cannot deliver detailed information on each disease. You may prefer a more in-depth approach as opposed to a rather general one and decide to extend the former service with your own.
If you find out that a service for this condition already exists, you might like to offer to help in some way. Alternatively, there may be a local branch where you will be able to meet other patients on a regular basis.

1.1.1. Questions related to the service activity

WHAT DO WE WANT TO ACHIEVE? WHAT FOR, FOR WHOM? HOW?
Practices must always be adapted to the aim:
What?
• What kind of information (medical information on the disease, on its treatment, on social aspects, on financial support…)?
• Which rare disease?
• What degree of language (complexity) is acceptable?
For whom?
• To whom is the information targeted (group, individual, patient, parent, relatives, doctors)?
• Which country?

How?
• In which context?
• With an open mind.
When defining the disease, it might be useful to consult with Orphanet to best select the medical entity(ies) you want to address. For example, if you intend to create a service on growth retardation, you should be aware of all conditions that can be included, and for each one, which are the synonyms. Synonyms, or related conditions, are numerous, as listed below, and you could end up with a much longer list than you expected:
  • Alopecia macular and growth retardation
  • Atrichia mental and growth retardation
  • Blepharophimosis nasal groove growth retardation (Die Smulders Droog van Djik syndrome)

• Cartwright nelson fryns syndrome (Growth retardation mental retardation phalangeal hypoplasia)
• Cataract aberrant oral frenula growth retardation (Wellesley Carmen French syndrome)
• Fallot complex mental growth retardation (Bindewald Ulmer Muller syndrome)
• Gapo syndrome (Growth retardation alopecia pseudoanodontia optic atrophy)
• Growth retardation hydrocephaly lung hypoplasia (Game Friedman Paradice syndrome)
• Hydrocephalus growth retardation skeletal abnormalities (Winter shortland temple syndrome)
• Intrauterine growth retardation mandibular malar hypoplasia (Fernhoff Blackston Oakley syndrome)
• Mental retardation – unusual facies – intrauterine growth retardation (Pitt-Rogers-Danks syndrome)
• Multiple congenital abnormalities mental retardation growth failure cleft lip palate
• Myopathy growth and mental retardation with hypospadias
• Short stature microcephaly seizures deafness (Boudhina Yedes Khiari syndrome)
• Prader-Willi syndrome
• and 68 other syndromes where growth retardation is one of the symptoms.
Despite significant differences, growth retardation syndromes share common aspects: medical experts, research programmes on growth, some treatments, care centres, etc…

The rarest of the rare diseases may never have a specific information service nor a patient group and to join together people affected with a common symptom is a way to move forward. However, some organisations may already exist, that more or less address growth retardation. For example, Prader-Willi syndrome groups exist in every European member state. So prior to launching a new service, it may be useful to contact organisations that are already operating to discuss the possibility of distributing tasks among each group or to develop common services, keeping in mind specificities that can justify the creation of a different service.

WITH WHOM?
• People Living with Rare Diseases : should be referred to the specialist in their condition; more than one specialist needs to be available, regardless of country and the skill of the doctor, to be sure the patient and doctor can develop a positive relationship.
• Link with other organisations at national and European level: firstly, securely establish your own service; secondly, link with other rare disease services in your own country; thirdly link with other rare disease services at European level.
• Develop a mentoring/partnering system to learn from a more experienced group in the same area of operation at national and European level.
• Structure the new group with a mission, action plan and strong committee to get started. (see Toolbox 7.3, page 6)
• Establish a network, 'patient helping patient'. Give patients all possible supportive contacts.

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1.1.2. Questions volunteers should first debate or address themselves

You are thinking of joining a group or starting a service because you see the benefits of bringing together other patients with the same condition as yours or parents of children who share your own child's condition. It is helpful at this stage to consider what is most important to you - would you be happy just being in contact with another person or do you think there is a need for something more structured?
You should carefully consider whether joining or starting a group is right for you and your relatives and friends and whether now is the right

time. You can always reconsider your position in the future if you decide not to go ahead at this stage.
Once you start, you will be getting enquiries from all over the country. It is unlikely that you will be able to meet with any other patients or parents at this stage. However, contact by letter and telephone can be just as effective in building support and sharing experience and information.

WILL IT INTRUDE ON MY PRIVATE LIFE?
The support of your relatives and friends in this

venture is essential. It will help to organise the time you spend on the group so that it does not intrude too much on your life. It will also help if you can share group tasks with others. If you are a parent, you should make other parents and professional workers aware that you are a parent caring for a child with the same condition. Telephone calls can be the most intrusive element to deal with, especially in the evening when you are trying to put the children to bed. Putting on an answer phone to take messages at these times, or arranging a mutually convenient time to call back, are possible solutions. It is better to contact other parents when you can give them your full attention rather than rush a conversation.

HOW MUCH TIME WILL IT INVOLVE?
This is difficult to predict and will depend largely on the rarity of the condition and the suspected number of affected people. Raising awareness of the group's existence in the early stages, through letter writing and personal contact, will take time. However, this responsibility could be shared with other people. As the group develops the time needed may be less. It may help if you allocate a certain time in the day to deal with tasks, such as responding to letters.

1.2. How to structure the activities?

The group can be structured in working groups according to its goals (like Alliance Maladies Rares in France):
• Working group on specific information sources
• Working group on orphan drugs
• Working group on multi-disability
• Working group on inclusion
  in mainstream school
• Working group on bio-ethics
• Working group on prevention
  and early diagnosis

• Working group on social rights

It is not necessary for groups to provide a wide range of information, hold events, raise large amounts of money or register as a charity, although some groups will want to do all of these things. There are many very small and informal groups in existence which provide a valuable service to the families they are in contact with.
All groups are different but they usually fit into one of the following categories:

Type	Activity
Website	Website with information about the condition and usually details of how to access a chat room or message board facility for members. There may or may not be a telephone number to contact a representative, but if there is no telephone number, this will exclude people without Internet access.
Patients' network	These usually have a small number of people who contact each other on an informal basis. The aim is simply for people to provide mutual support. They need a contact person who will link in any new patient/family who makes contact.
Contact group	A group with a larger number of patients taking on more functions e.g. newsletter, annual event. It may be a registered charity or considering registration.
Support group	A larger group with a committee, list of aims and formal membership. It is likely that a group of this size will be a registered charity.
Umbrella organisations	These provide support and representation for a number of related disorders e.g. Headlines for craniofacial conditions and CLIMB for metabolic disorders in the UK.

A network may be the best option where;
• The time you have is limited
• There are only a very small number of families affected by the disorder in your country
• You want to concentrate on support and contact with other parents
• You are not looking to set up a formal group

Even if you would like to set up a more formal group it may be best to start with a network while you contact other people and they decide if they are interested. This may take some time. When you have a number of people interested in running a group you can then make things more formal.

Resources and funding 1.3.1.

Many groups falter or fail because of funding. With many organisations operating on limited budgets, a large-scale campaign may be difficult without additional sources of income. The costs of travel, communications, resource development, and training can hamper efforts to build the service. A group needs to survive beyond a key individual (usually the founder).
Some costs will be incurred in the early stages, but these should be minimal and will include postage, photocopying and paper. As the group develops, small fundraising events may provide the money needed to keep the group going. Some parents may come up with alternative offers of help, such as providing stamps to send out information. Remember the private sector, especially local businesses.

Dutch organisations can benefit from 110% funding from the State (financial provision) (like ADCA, Autosomal Dominant Cerebelar atrophy/ataxia, in The Netherlands). This secures the organisational budget.

Feasibility studies 1.3.2.

FOUNDING MATERIALS
The following documents are essential: they should be agreed upon prior to starting the service. They will facilitate the service implementation (as a shared reference document) and guide you when running the service and evaluating it.
• Mission statement (see paragraph below)
• Disease description
• Constitution or convention (much depends on National rules and customs)
• Business plan (see paragraph below)
• Protocol for service monitoring (confidentiality rules...)
• Guidance for self-evaluation (see paragraph)

MISSION STATEMENT AND GOALS
This document describes the purpose of the organisation, the reasons why it exists. The mission statement can be broad to reflect the philosophy of the group and permit a wide range of other groups and individuals to participate. An organisation's membership symbolises an endorsement of the mission and commitment to the goals of the service.

A clear mission, understood and shared by every member of your group, provides focus, by driving strategy, and control by guiding execution. Developing one is difficult and time-consuming. It must inspire but be feasible, engage the heart but convince the mind and stir deep passions but result in practical actions. It must be guided by the organisation's leadership but shared by everyone.
The mission statement reinforces the shared connections between members and provides guidance on which other organisations should join.
A Mission Statement can be as short as one sentence and should be defined in just one short paragraph. If you can't do it that concisely, maybe you're not sure what you really want to do.

Example of a mission statement:

Cystic Fibrosis Slovenia mission

The Association of Cystic Fibrosis Slovenia (CFS) is a non-profit, patients' organisation dedicated to the enhancement of information services to people with cystic fibrosis and their families. Created in 200_ by patients, relatives and health professionals, CFS is a multidisciplinary force for improved care for people living with cystic fibrosis.
Mission Statement of the Association of Cystic

Fibrosis Slovenia
To advance excellence in the information and care of people with cystic fibrosis, their families, and caregivers through:

• information services
• Advocacy
• Education
• Networking
• Research
• Resource Development

Phase	Theme
Analysis	**Who am I?**
	Main idea project What is already available: supply and demand in the domain
Planning	**Communication / outreach and awareness strategy**
	Financial planning and budget estimates at one year, at three years (or five) Technical options Legal and Organisational form
Operations	**Who does what, when, with what resources**
	Operators/volunteers and staff training Code of conduct/code of operation Enclosure to back up business plan assertions

DISEASE DESCRIPTION

- Develop a document that describes the disease, its treatment protocol and how to manage day-to-day (see Metachromatic Leukodystrophy Brochure published by CLIMB as a basis document, annexe 8.1 page 19).
- The first meeting with specialists or reference experts to discuss the disease is important. A follow-up meeting is equally important.

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CONSTITUTION - MEMORANDUM AND ARTICLES OF ASSOCIATION[1]

Constitution and articles of associations are the legal rules that govern the organisation in a given country. In parallel you can develop by-laws, internal rules by which its internal affairs shall be dealt with. By-laws are usually not legally binding. A general assembly is not mandatory to change them. For example, the Constitution can create a membership fee, not mentioning an amount. The membership fee amount appears in the by-laws that are revised annually by the management board. In doing so, you avoid having to change your Constitution every time you need to change the membership fee. Changes to the Constitution must be officially registered in most of Member States, and you may prefer not to go through this process too often.

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[1]
Conseil de l'Europe, Glossary E-F, Strasbourg, 1986 : a document, essential by law, recording article by article the way in which a company shall be managed.

SELF-EVALUATION

It is recommended your group should have a minimum standard of Good Practice for Quality Assurance. Chapter 5 proposes methods to evaluate the information service. Basically, they consist of evaluating whether enquirers are satisfied with the information provided, both qualitatively and quantitatively. But there are other domains you may want to evaluate. These might include: procedures for recruitment and training of staff, proper time allocation to regularly review work processes and organisational aims to be sure the group is still delivering information in accordance with its aims and needs and the impact of awareness campaigns.
Each volunteer or each staff member could be

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evaluated by peers. Another approach is to conduct self-evaluation, for example each person could complete an evaluation form at regular intervals to address questions like "relations with others" for personal improvement (see Toolbox 7.11, page 13).

BUSINESS PLAN

A business plan is a written support that helps your stakeholders (Foundations, Fund providers, health authorities, local authorities, banks…) to understand fundamental aspects of your project both from financial and operational points of view. In the context of the creation of an information service, it facilitates the evaluation of the ambitions, scope, objectives, means and resources of the group. A consultant could be hired to build the business plan. Alternatively use working groups to develop the action/business plan (see Toolbox 7.3, page 6).

In general, a business plan should summarise useful information for the project :
- Key people
- Proposed service(s)
- Targeted patient population(s)
- Communication strategy to publicise the service
- Legal aspects
- Budget

A business plan not only helps you present your project to possible partners, it may also serve as a matrix guide for establishing the project. It is not only intended for potential investors or funders, it is a real guide book for you to pilot the project according to detailed specifications that you have decided upon. However, it carries the risk of appearing "business like" with a less personal touch (see Toolbox 7.4, page 8).

On line services exist for business planning in various languages. As an indication, you can find such a service in the Czech Republic by following these URLs:
http://nno.ecn.cz/
http://www.ecn.cz/nno/ekonomica.

Identify resources among volunteers and staff   1.3.3.

Early in the group's development, all volunteers should identify what they can offer it. For example, volunteers may be able to provide a few hours of secretarial support each month or host meetings in their offices. Others may be able to conduct research or focus group discussions. This process will set a precedent for new volunteers as they are invited to join. Engage youth in the organisation.

Start small.
It is important to lay a solid foundation first. Start with a limited number of staff/volunteers from a defined geographical area. A small group is easier to manage, makes communication less expensive, and helps volunteers/staff identify achievable goals and objectives which will help guide later growth.

Resist the urge to build the group too quickly.
Consider which new partners will best support the goals of the group and invite them to participate.

Requirements on handling of personal information   1.3.4.

To ensure data confidentiality and to respect privacy, Member States and the European Union have adopted a series of rules and laws[2]. Overall, personal information may only be handled for specified and justifiable goals (see Annexe 8.3, page 20).
- Collected information may only be used for the purpose for which it was collected
- Personal information must be correct and up-to-date and must not be kept for a longer time than needed for the purpose of the collection
- Personal information may only be handled with permission from the person, whose information is handled, or for certain other justified uses
- A supervisory authority can control the use of computers for storing and processing personal data.

- Those who wish to store or process personal data must either have permission from this supervisory authority or, in some cases, inform this supervisory authority. The authority may then regulate what personal information is to be stored and how it may be processed.
- People, if their personal information is stored in computers, must be notified of this, and/or may request a copy of what is stored about them and then can request that incorrect information be corrected.

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[2]
DIRECTIVE 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.
Guidelines on the protection of privacy and the cross-border flow of personal data, established by the organisation for economic development (OECD) 23 September 1980.

Convention of 28 January 1981 for the protection of individuals with regard to automatic processing of personal data, established by the Council of Europe. Proposal for a directive concerning the protection of personal data and privacy in the context of public digital telecommunications networks, in particular the integrated services digital network (ISDN) and public digital mobile networks, prepared by the European Community in 1990.

- Electronic mail systems include directories of users and what they have written. These are typical of the kind of personal information for which the computers and privacy legislation was intended, and there is usually no problem in applying the legislation to such information.

Implementing this Directive, Member States are in the process of adopting national laws. Refer to your own legal system for accurate interpretation in your country.

SENSITIVE INFORMATION

It is usually not permitted to handle personal information which reveals race or ethnic origin, religious or political opinions, membership in trade unions and information about health or sexual behaviour. There are a few exceptions to this. A society may handle information about its members, even though the organisation is connected to a particular religious faith or political view, and medical organisations may handle medical information about their patients, researchers may handle information for research purposes and such information may also be handled or published with permission from the person whose information is handled.

TRANSMISSION TO THIRD COUNTRIES

Personal information may not be transmitted outside Europe without permission from the person whose information is handled, except with explicit permission from this person and only to fulfil legal

obligations or to protect vital interests.
Data processing is only legitimate if, among others:
- The subject has unambiguously given his/her consent
- Processing is necessary in order to protect the vital interests of the data subject

SPECIAL CATEGORIES OF PROCESSING

Member States shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life. This does not apply where processing of the data is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services, and where those data are processed by a health professional subject, under national law or rules established by national competent bodies, to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy.
The text in electronic mail messages will, of course, often contain personal information, often exactly the kind of information which such rules say should be controlled with particular care. They may also contain data concerning a person's sex life. Personal messages may also, of course, contain information about health: for example, someone sending a message that they cannot come to a meeting because of illness or giving health advice to friends with health problems, etc...

1.3.5. Information service evaluation

An evaluation system is the means by which an organisation determines the impact of its programmes on the areas on which it focuses. It is recommended that you plan to evaluate the information service shortly after starting activity: this will demonstrate to your sponsors and funders that your goals are reasonable. Chapter 5 explains evaluation in further detail.

1.3.6. Technical requirements

- How do I know which equipment to buy for our helpline?
- Analogue or ISDN lines - what is the difference?
- What do I need to think about when buying an

  answering machine for my helpline?
- How do I monitor calls (see chapter 2.2.1 on **Telephone lines**)?
- What about confidentiality issues?
- What has worked before?

1.4. Points to consider when creating a group

1.4.1. Share information among members

At the initial stages, it is important that members spend time learning about the roles and expectations of others in the group. This information sharing will help build understanding and trust among members, as well as provide useful information about the service's interests, strengths, conflicts, and weaknesses.

Develop objectives and strategies 1.4.2.

Objectives are specific and measurable items to be accomplished in your organisation's efforts to attain its goals. A clear set of objectives will define the specific policy changes that the service aims to achieve. Objectives must be specific, achievable, and measurable, and serve as a means of evaluating activities. Strategies may include a public education campaign, direct appeals to a specific leader to change a policy, or lobbying government to pass a law.

Objectives are internally focused, indicating desired results for specific internal teams and people. Performance against these objectives will be the primary indicator for judging whether or not the organisation's goals are being achieved. A well-formulated objective should:
- Start with the word "to" followed by an action achievement verb (**introduce** product, **reduce** cost, **achieve** return);
- Specify a single key result to be accomplished;
- Specify a target completion date or time period;
- Make a real contribution towards achieving the relevant goal.

Create and follow a realistic time line 1.4.3.

A realistic time line is one of the most important tools for a group. From the initial meetings to the first activities, building a functioning group can take months or years. An achievable time line, with targeted activities every trimester, will help ensure the group remains focused on its goals and realistic in assessing different activities to be considered.

Establish a structure and leadership roles 1.4.4.

Organisations/groups are most effective when all members/operators have a voice and know they will be heard. Nonetheless, the group must have leadership and structure. The members should choose at least one chair and clearly define the chair's responsibilities.

Share responsibilities through committees 1.4.5.

Committees allow more people to participate actively, and can be either permanent or limited to a specific project. Define responsibilities and the decisions that committees can make without full service approval. Expand the base.

Hold regular meetings 1.4.6.

Hold meetings often enough to respond to current events and on a regular basis - at least monthly. Hold meetings at a convenient time and location for all members; strive to start and end on time. Consider whether meeting times should rotate between day and evening hours and vary in location.

Keep people informed 1.4.7.

Maintain up-to-date mailing, phone, fax, and e-mail lists for key contact people. Keeping members/ operators informed maintains trust, interest, and involvement. It also minimises misunderstandings and identifies points of disagreement before they become problems. Members should always receive minutes from meetings, updates, news clippings, and information on future events. Adequate advance notice of meetings and other events encourages participation in important discussions and decisions.

Select spokespeople who will represent the organisation to the media 1.4.8.

Early in the group development, identify members who have experience in public speaking or interacting with the media. The spokespeople may or may not be the same people as the leadership

team. Members should agree on a process for handling enquiries from the media.

1.4.9. Raising awareness of your information service

During the early stages the most important tasks will be making contact with other patients/parents and raising awareness of the group's existence. You will probably have to write to interested professionals to let them know that a group is being set up and ask them to pass on the information to other people. You may want to draw up a standard letter that could be sent out to interested patients/parents, introducing yourself and telling them what the group is trying to do. You must stress to patients, parents or professional workers that you are not a medical information service - if you do have some information on the condition it should be clear that this has been written by a medical professional who is a specialist in the condition.

Good practice :
Write information by translating documents produced by other groups, adapt them to the needs of your own group and update them regularly. When doing so, it is recommended that you mention the source of the document and the initial language.

1.4.10. Practices to avoid or to be cautious about

The following practices may raise concerns and lead to difficulties. In general, they should be avoided or the information service should be cautious when using them:
• Using forums on a website without proper training/controls
• Networking with diagnostic laboratories or the pharmaceutical industry
• Home visits to assess needs
• Photographic records that trace the natural history of the disease (enlightening to some, shocking to others)
• Pack of consistent quality training whether staff or volunteer
• Inviting politicians to meetings in the belief this will influence health policy

Networking with diagnostic laboratories may create confusion: some laboratories may be tempted to use your organisation as an advertising tool. Of course some laboratories are better than others, and your group may prefer to inform on those that appear the most rigorous and serious. As "seriousness" is very subjective, and different people can have different experiences with the same laboratory, it is not always possible to rate laboratories according to rational and standardised criteria. Be aware of such biases, and always try to keep away from experiences that would be too personal.
Home visits are sometimes proposed as a first contact, and then they can be conducted on an as needed basis. This may help defining which technical aid is needed (home medical equipment, ergonomics, lifts…). By visiting private homes, you may discover extremely difficult living conditions and problems that patients and their families are facing every day. It is most important not to be judgemental, and to ensure the highest confidentiality.
It is also essential to establish strict rules with regard to your personal safety when visiting someone's home. Ensure that your group knows where you are going, why and for how long. Take a mobile phone (Victim Support Guidelines, UK).

Other advice can be obtained from Contact a Family in the UK. This organisation has issued a series of guides for the creation of patients' groups. Some can be downloaded from the website:
www.cafamily.org.uk.

General principles 2.1.

How to validate the information: It always takes time! 2.1.1.

Good information relies on proven facts, not on impressions, anecdotes, rumours or misinformation. As obvious as it may seem, it is not always self-evident. With the greatest of good faith, nobody can always ensure delivery of the truth. If you were asked to describe the shape of a raindrop, you would probably describe the common teardrop shape. Actually, real raindrops bear scant resemblance to this popular fantasy (except after they have ceased to be raindrops by splattering on a window)[3]. Truth, or what you think it is, is never put into question often enough. Validation is a dynamic process : a fact may be true one day, less true the next day.
In order to validate information, which means finding or testing the truth of that information, you can :
• Find precise quotes with references (complete and standard ones, see annexe 8.7 page 24)
• Check with social law reference books
• Check with scientific sources
• Consult with a scientific committee or external consultants
• Liaise with colleagues

• Consult with umbrella organisations where interlocutors are clearly identified

In some situations, the provider of information has a legal duty to verify the source and the quality of the information (this applies for example to CNMR, The National Centre for Rare Diseases in Italy, as it is part of the Istituto Superiore di Sanità, National Institute for Public Health and Research).
In any case, working as a team with medical professionals can be considerably helpful.
An open question about validation is, from whose perspective? Who is expert on what between the doctor and the patient? What is evidence? What does it mean "published", "consensus", "experience", "rules of engagement"?
Articles in periodicals of professional societies about the disease are already validated and are therefore a good source of information.

Professional societies have set up criteria to define the level of validity for each fact/information. For example, medical facts can be ranked as shown in annexe 8.2 page 20.

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How to do it 2.1.2.

Case management approach, as done by the MPS Society in Great Britain (Society for Mucopolysaccharide Diseases), consists in making collective responses to queries as they come in.
A very common approach is to hold internal meetings (for example on a weekly basis) to review submitted questions (calls or e-mails), not always on the same day each week, for all volunteers to be able to participate.

In the annexes, you can find one example of an enquiry form developed by FEDER (Spanish federation of rare diseases). Each respondent (whether e-mail or telephone) is invited to complete it after the contact. This helps to keep track of enquiries, for instance to assess the information needs of your enquirers (see Toolbox 7.8, page 10).

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Different enquirers, different questions 2.1.3.

Most enquiries will come from parents, family members or friends of the patient. Professional workers, such as health visitors, social workers and community workers may also contact you for information, usually because

they are involved with a patient or a family caring

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Small raindrops (radius < 1 mm) are spherical; larger ones assume a shape more like that of a hamburger bun. When they get larger than a radius of about 4.5 mm they rapidly become distorted into a shape rather like a parachute with a tube of water around the base and then they break up into smaller drops. See Pruppacher and Klett, Microphysics of Clouds and Precipitation, (1978, Reidel, Boston), pp. 316-19

for a child with this condition and would like to know more about it. Occasionally there may be enquiries that may be better referred onwards, such as where an enquirer has not been given a diagnosis but thinks he/she may have the same condition. Here, it is best to help by referring the enquirer to a medical expert or to related organisations that offer general support while he/she is seeking a diagnosis.

- Patients: frequent questions relate to an address for the best centre for diagnosis and care, prognosis and disease progression and quality of life.
- Families: how to prepare for the future, at school, or after parents are dead, if there are risks for other births.
- Doctors: contact with colleagues at national and international level, research projects, new therapeutic options.

2.1.4. Content

- When asked, general information on life expectancy is given by a medical advisor. It is not appropriate for a lay person to predict disease progression. Statistics that apply to a group of people cannot be extrapolated to a single individual.
- Good practice: Do not give information about the extreme parameters of the disease; rather adjust it/pace it according to an enquirer's needs. Work out how to be truthful about the disease without causing alarm/fear, how much to tell, how soon.
- For disease evolution in a child: respondent should remain cautious.
- Create a handbook to deal with the transition of care from paediatric to adult and the transition of education as its main elements.
- Consider publishing a reference book for couples and families regarding basic genetics (sporadic genetic change as compared to transmitted mutation etc.), screening and prevention/early diagnosis of inherited disorders.
- A response is not a remote medical visit: it can validate and re-explain information given by a treating physician that was not fully understood.
- Receiving/giving balanced and neutral information on medicinal products.
- When a diagnosis is unknown, more research should be done or the enquirer should be directed towards a specialist. It may not be possible to identify the appropriate expert immediately, but, for example, an endocrinologist or a gastro-enterologist should be consulted for a disease that provokes metabolic disorders. It may not be his/her speciality, but the endocrinologist should be

- Health authorities: status of orphan drugs, list of designated orphan drugs.

ADAPTING INFORMATION TO LIFE EVENTS AND AGE OF PATIENT

Based on different enquirers' profiles and expectations, information can be organised according to the different stages of the disease and different life events. For example, typical stages can include:
- Infants
- Pre-school childhood
- Childhood and schooling
- Puberty/adolescence
- Young adults
- Graduated and young job seekers
- When relatives and parents are present or missing
- Pregnancy and desire to give birth

able to refer you to an even more specialised colleague if necessary.
- "Invisibility" of condition, i.e. symptoms are there but "non-specific" so diagnosis is late – rare disease patient feels neglected.
- Send positive articles from newsletters
- When there is no diagnosis, some information can be sent to the person, encouraging them to see a medical doctor.
- High genetic risk diseases – enquiries often have genetic concerns as a priority for self or relatives.
- Bad/hyped news by media can raise awareness for a short period – can be hard to handle
- Keep abreast of new developments.
- Signposting, facilitating referral to appropriate specialists.

Technical and logistic aspects
- Volunteers can respond from home, according to their availability.
- Line should be open at different time periods:
  - During working hours: staff able to respond, medical doctors and consultants available.
  - After working hours, in the evening or during weekends: more convenient for some volunteers, as parents or patients have more opportunities to call at these times.

List of contacts
List 1: disease repertory, patients' organisations, self-help groups.
List 2: members' register, patients' register (confidential information) to communicate events, meetings, General Assembly...
List 3: reference centres, national/regional experts, research institutes, pharmaceutical industry.

2.1.5. Oversight committee

A model is the oversight committee created by Maladies Rares Info Services.
Its role is:
- To audit respondents
- To audit doctors (external consultants)
- To evaluate the service
- To design ethics and deontology guidelines

- To conduct a user survey to check satisfaction levels
- To study forms being created for the service (data collection, responses, mail, etc...)

The oversight commitee can be composed of some members of the board of directors or trustees, volunteers, staff and external experts.

2.1.6. Questions to ask of the enquirer (not immediately, but early in the discussion)

- What do you know? To give information little by little, to verify it is well understood, taking account of an enquirer's present need for knowledge. Introductory information first, then additional information according to the

enquirer's reaction and comprehension.
- What would you like to know (as precisely as possible)?
- What kind of needs do you have or what kind of service do you need?

2.1.7. Frequently asked questions (areas to know well and keep up to date on)

- Fiscal and social law
- Financial support
- Therapy, medicinal products
- Clinical management
- Where to get a diagnosis? Where to verify a diagnosis? How to be sure of the quality of a test? What other diagnostic procedures exist?
- Specialised clinics

- Psychotherapy
- Where to find brochures?
- Life expectancy
- Genetic testing and counselling
- Health insurance, bank loans
- Recent scientific progress made during the last 20 years (when available)

2.1.8. Children, teenagers

A different advisor than for other family members, to be as professional and respecting.
Good practice:
Involvement of patients' school to ensure good

care in school hours by using an active or retired teacher on the staff of the organisation; be sure teachers receive adequate information on pupil's rare disease.

2.1.9. Training

On how to answer a telephone call:
- Collective sessions with a teacher (initial session for one week, then followed up by a one-day session one week later)
- Double-listening and call follow-up training (passive way, then active way when advisor feels ready)

To provide training with social workers and medical advisors. Training on how to take care of symptoms/side effects of treatments.

Some enquiry lines recruit social workers with psycho-sociological expertise and education. Others recruit volunteers from the organisation and train on-the-job.

When no specific training is organised, volunteers, parents and operators usually share their experiences as a minimum.

Procedures specific to certain information tools 2.2.

2.2.1. One-to-one services

TELEPHONE LINES
What skills will be needed?
It is important that you know how to listen

and respond sympathetically and sensitively to enquirers who telephone or write to you. For many you will be the first person they contact

who has some idea of what they are experiencing. You should be able to write letters that are supportive and it is essential to deal promptly with enquiries. Organising your time and the workload are important skills, especially as you will have other family commitments. As the group grows you will be able to involve other volunteers/staff in sharing tasks.

Pros and Cons[4]

	Pros	Cons	Most effective use
Telephone services	• Direct contact with enquirer, possibility to check clarity during conversation • Questions & Answers optimised • Possibility to investigate and send back "à la carte" or personalised responses	• Emotional • Operator can be surprised by a question he/she does not know how to respond to • Operating hours driven by enquirers	• Sign-post on questions to experts • Written answers possible • Confidentiality procedures

The group can choose to take some or all calls anonymously (no personal data or follow-up calls), offer the possibility of a call back at a convenient time, or to provide access to a free phone number.

Three way approach to caller
1. Relieve loneliness and anxiety
2. Provide a solution to a problem
3. Provide technical and practical information.

Training
The Telephone Help Lines Association proposes training for telephone line operators. The Programme consists of three phases:
• Core Helpline Skills
  Use active listening and effective questioning skills when working with callers
  Provide relevant information to callers and make appropriate referrals.
  Be aware of strategies for ending calls, including those that are abusive.
  Be aware of the possible boundaries of the helpline service.
• Advanced
  To explore the management of complex and challenging call situations in a supportive environment.
  Use reflecting and paraphrasing skills when working with callers.
  Carry out an assessment of the needs of callers.
  Implement strategies for dealing with challenging calls.
• Counselling skills for helpline workers
  Of particular relevance to help lines who offer listening, befriending and emotional support services.
  Use a variety of active listening.
  Respond with empathy to the caller.
  Hear the feelings behind the words and reflect these back to the caller.

Work with callers when there appears to be "no solution" to their problem.

Setting up help lines
Have an in-depth practical understanding of the range of considerations that need to be taken into account when setting up a helpline.
Understand the importance of monitoring and evaluation and establish appropriate processes.
Identify issues around the necessary staffing to run a helpline effectively.
Develop appropriate policies and procedures for a helpline.

Helpline evaluation and monitoring
Be able to identify appropriate roles and uses of helpline volunteers.
Have an understanding of volunteer motivation and the internal and external factors affecting recruitment.
Have an understanding of effective recruitment and selection processes for helpline volunteers. Have an understanding of the expectations of helpline volunteers including: volunteer agreement forms, training, support and supervision (see Toolbox 7.9, page 10).

MONITORING THE SERVICE
Know-how
• Operator could respond first, and then a medical doctor can continue with more personal issues. Professionals prefer to receive written materials.
• In order to best understand each person's itinerary, it is necessary to invite them to speak in great detail. But requested information should not be systematically or immediately provided: in-depth questioning without being inquisitive may help, and sometimes the conversation must be reframed.

4|

Starting and Running a Non Profit Service by Joan M. Hummel, University of Minnesota Press, London, 2002.

• For difficult questions sent by e-mail, response could consist in asking the enquirer to call back. This provides further delay to discuss difficult questions with the team.
• To be able to rephrase precisely what the concern/problem/situation is.
• To ask the enquirer to rephrase the information provided in order to verify it was well understood.
• Language is an obstacle if the information is not in the mother tongue.
• As enquirers can call several times for the same question, different people may respond. It is therefore important to co-ordinate responses.
• For migrants or travellers (language line services): over-the-phone translation exists in some countries but this service is expensive.
• People are all different, you must adapt to them.

• Try to release the tension.
• As a model, a conversation can be organised into four phases:
  • Listen to the person's story. Rephrase it to make sure problems and concerns are well understood
  • Provide "soft" and "progressive" information first, to analyse how the person is reacting
  • Give more information, not necessarily all the information available
  • Propose another call, a follow-up, leaving more time to check with specialised experts.
• Put information into layman's terms.
• More information can lead to new uncertainties.

Website 2.2.2.

More and more groups decide to develop their own website.

Information posted on a website should be progressive and accessible to all education levels. All questions must be responded to.
Realise that not everyone has access to the Internet and that not everyone is familiar with how to research on the Net.

A CODE OF CONDUCT
A code of conduct for websites related to health has been developed (see annexe 8.4, page 20). You can find more information and translated versions on this site : www.hon.ch.
Some organisations propose guidance on how to find information on the Internet. For example, VSOP in The Netherlands edits a brochure "Unknown makes Unloved", for patients with no existing support group (it has tips on how to find more information in the library and on the Internet):
• Look at the website of the Dutch Patient and Consumers Federation. All known patient organisations are listed on this site.
• You can also go to the website www.erfelijkheid.nl or to the Erfocentrum
• You can type the name of a disease in a search engine, e.g. Else (Dutch site), Google or Alta Vista. This will find a lot of different sites, but it may be difficult to find what you are looking for.
• If you know what type of disease it is (e.g. muscular disease, metabolic disease, blood disease) you might be able to find an umbrella organisation (e.g. Vereniging Spierziekten, The Netherlands, for all muscular diseases) which can help you further.

• Sometimes information from the Internet is difficult to understand because it is not in your native language or it has a lot of difficult medical terminology etc. Therefore, discuss all the information you find with your treating physician.
• On www.lefwijzer.nl you can find links with information on certain diseases, some also international. You can also find information on insurances, legal issues, care, work and disability, social security, etc.
• Links are also given to some sites with relevant information on the Dutch security system.
• Links are given to the sites of the Dutch ministries, insurance companies, the Dutch pharmaceutical industry organisation, Dutch research umbrella organisations etc.
• Also ask your physician for relevant links on the Internet.

CREATE YOUR OWN SITE
For an investment of 1250€, you can have a website with the following characteristics:
• Your own domain name, to be renewed every year: www.cysticfibrosis-slovenia.org (for example)
• DNS registration
• Server provider
• 12 pages: home page (who you are), presentation of services provided, who you are working with, information on the disease(s), references and links, list of reference centres in hospitals, how to contact you.
• 10 Mo hard drive space, basic Mysql, Php3, several e-mail addresses (e.g. postmaster @cysticfibrosis-slovenia.org, webmaster@, president@...)
• Group picture (service directory)

- Practical functions:
  - e-mail this page to a friend
  - bookmark this page
  - integrated search motor
  - navigation optimised for the disabled (w3c protocol)

- easy updating
- advertising space
- listing of your site in 6 search engines: Yahoo, Alta Vista, Lycos, Voila, Nomade, Hotbot.

	Pros	Cons	Most effective use
On-line services	• Well-educated and involved audience • Accommodates Questions & Answers • Can post messages quickly • Easy to update	• Requires computer, modem, software, knowledge • May involve fees for access • Posting must be non-commercial	• Quickly mobilise people with like interests

ACCESSIBILITY TO INTERNET

Many conditions limit the physical ability to use the Internet. Guidelines and services have been developed to help solve these difficulties. See in particular: http://www.w3.org/WAI/, Web Accessibility Initiative supported by European commission.

To validate your website's accessibility, see annexe 8.6, page 23 "How do I validate my Site for Accessibility?"

IMPAIRMENTS[5]
Visual impairments
- Blindness
  Users can have software which translates text into speech. The user therefore hears rather than sees web pages. Often (incorrectly) thought to be the main category of users where accessibility is an issue. The BBC provides software called Betsie http://www.bbc.co.uk/education/betsie which converts pages (in real time) into a format suited to text-to-speech software.
  Also, you can check what your pages look like in very early browsers by using either Dejavu.org's browser emulator:
  http://www.dejavu.org/emalutor.htm or Delorie.com's Web Page Backward Compatibility Viewer http://www.delorie.com/web/wpbcv.html.
- Partially sighted:
  Users who either use screen magnifying software or need to enlarge the size of text on screen. This defines a large category of users which spans from users with low vision to users who are more comfortable with being able to alter text size.
- Colour blindness/colour deficiency:
  This is an extremely varied condition. You can simulate one aspect of colour blind vision by using the http://www.vischeck.com/vischeckURL.php3 Image Engine.

Hearing impairment, mobility, seizure disorders
- Hearing impairment
  An issue only if you use sound files or video with sound in your web pages. Provide a text description of any sound files and the full text of any dialogue.
- Mobility
  Users may have difficulty in accurately and/or quickly moving a mouse around the screen. Avoid the use of small link elements. For example, avoid using either bullet points or the first letter of a word as a link. Where long lists of links are necessary, provide links to enable the user to skip between sets or sections of links.
- Seizure disorders
  One straightforward guideline: Avoid the use of elements which flash in the range 2 - 55 times per second.

Participation for all in the knowledge-based economy
The Lisbon European Council[6] recognised that *special attention should be given to disabled people and the fight against "info-exclusion". It indicated that real efforts must be made by public administrations at all levels to exploit new technologies to make information as accessible as possible.*

The challenge
As government services and important public information becomes increasingly available on-line, ensuring access to government websites for all citizens becomes as important as ensuring access to public buildings. In the context of citizens with special needs, the challenge consists in ensuring the widest possible accessibility to information technologies in general as well as their compatibility with assistive technologies.

In addition, new technologies can often be easier for everyone to use if the usability requirements of all potential consumers are considered from the beginning of the design process.

The e-Europe response
Public sector websites and their content in Member States and in the European Institutions must be designed to be accessible to ensure that citizens with disabilities can access information and take full advantage of the potential for e-government. In relation to "designing-in" accessibility to all information society technologies, training for designers in this area is relatively new and therefore fragmented across Europe. There remains much scope for mutual learning between centres of excellence to build a co-ordinated and high quality approach.
See e-Europe action plan in annexe 8.5, page 22.

Printed materials   2.2.3.

Write documents that people read several times, with different levels of information, adapted to their different needs.

Good Practice:
UK organisation (Climb) provides a folder with different documents, flyers, leaflets, and pages of information according to the needs of the enquirer.

	Pros	Cons	Most effective use
Brochure	• Control of message • Low-cost pieces can be effective • Mass mailing can be targeted to individuals	• Competes with many other items • Recipients may not absorb key messages • Difficult to secure immediate feedback	• Mailing list is up-to date with right individuals • Easy to read • Designed for both skim and detailed reading
Poster, billboard	• Control message • Can reach large group or target narrow audience • Usually easy to deliver	• Competes with many other items • Short message • Generally no immediate feedback • Can be expensive	• Short, quickly absorbed message • High-impact message
Print advertising	• Control message • Easy to deliver • Detailed messages possible • Can reach large audience	• Competes with many other advertisements • Advertisement in daily newspapers and magazines usually expensive	• Need quick delivery • Seeking response • Detailed message
Press releases	• Inexpensive • May reach broad audience or very focused public	• Publication can (usually will) edit news release • Strong competition for editor's attention • High impact difficult to achieve	• Simple announcement • Message will appeal to daily media • Want to reach people through weekly newspapers

MATERIALS DEVELOPMENT
Develop user-friendly training materials
Materials need to be developed as not every inquirer is connected to the Internet.

Develop guidelines
When risk of genetic transmission is high, you can consider formulating and distributing guidelines on genetic risk interpretation or reproductive health for parents and children.

Produce materials for difficult or sensitive topics
In some cases there may be a need to develop materials for sensitive or difficult topics. These might include: consequences of early marriage, unwed pregnancy, premarital sex, drug and substance abuse, rape, unsafe abortion, and male involvement in family planning.

Balance cognitive and affective behavioural contents

The materials should not only aim to develop knowledge and understanding but also to promote thinking activities, analysis, critical judgement and to provide many opportunities for practising skills. Messages and activities should be behaviour-oriented rather than dominated by theories and principles.

Consider religious and cultural diversity

Accommodate diversity in developing materials. Different cultural groups in the country must be able to relate to the content. If needed, materials may have to be produced in different languages and the choice of words must not offend particular groups.

Set up a comprehensive library of materials

Developers of materials should refer to this to avoid duplication in the production of materials aimed at the same problem and audience.
Make materials more interesting, more effective and more appealing to wider audiences.

HOW TO MAKE MATERIALS MORE APPEALING

Some ways to accomplish this:
- Use teasers as well as short, catchy, colourful and primer-type materials and messages. They are more effective than printed materials which are heavy on information. Such information can be given by a counsellor during face-to-face interaction.
- Design materials with specific target audiences - and their needs - in mind. If possible, involve young people in developing these educational materials to ensure better utilisation.
- Develop more adolescent-friendly materials, such as videos, audio-cassettes and websites.
- Use a variety of materials and media and do not rely on a single media format. The printed medium might be unsuitable for some target groups (e.g., those who are semi-literate or illiterate).
- Before preparing materials, call a consultative meeting to discuss the idea of producing them with representatives of potential users.They can then give suggestions on appropriate messages, format, and language. In this way, most materials produced can be shared by all; they can become popular and in great demand; contradictory and duplicative messages will be avoided; and time, funds and expertise will not be wasted.

EFFECTIVE USE AND DISTRIBUTION OF MATERIALS

Improve volunteers' or health workers' capability to use materials effectively.

The capability of mid-level health workers to effectively use materials as tools of communication should be improved. Such capability is needed

by these workers in government and with non-governmental organisations.

Widely distribute materials at strategic points

Information on a disease and information service may be provided to targeted audiences through various outlets, including health clinics or posts, social security services, health insurance programmes, counselling and family life education centres, youth and women's clubs/groups…

Produce self-sustaining materials

Produce materials that can sustain themselves through innovative strategies. Those interested in using the materials may be asked to produce it themselves and donate back a portion.

INNOVATIVE AND EFFECTIVE APPROACHES

The use of experimental and innovative approaches should be encouraged. Among these are: online chats and websites, on-line counselling, contact by fax and e-mail, mobile exhibitions, theatre, talk shows, television spots, drama serials, incorporation of messages into novels and short stories, the use of celebrities to convey messages, providing counselling and health services in schools, youth camps and youth clubs, observation of national and international days and education through sports or cultural programmes and activities.

Select and showcase programmes with "best practices"

The experience of successful programmes should be documented and made available for the benefit of other programme planners and managers.

Choose meeting places appropriate to the needs of disabled members.

	Pros	Cons	Most effective use
Speech or slide show	• Potential for dramatic portrayal of your programme • High impact • Questions & Answers opportunity • Longer message possible	• Takes time to arrange and time to write speech • Requires effective public speaking • If sensitive topic, Questions & Answers can be disastrous if not capably handled	• Need to reach small, key public • Need to reach opinion makers • Need high impact • Message is of high potential interest • Speakers are well trained and capable

ORGANISING GROUP MEETINGS

Regular meetings of the group or public information meetings, although perhaps difficult to organise play an important part in the running of the group and in the sharing of information. The number of meetings you will need will depend on the nature of the group and what you want to achieve. There are several things to consider when organising meetings:

- Members should be aware of their responsibility to attend meetings before agreeing to take on the role
- Meetings should be planned well in advance
- For national groups, try to vary the meeting venue around the country to balance the

travelling distance for each person attending
- Always have an agenda or a programme to work through – it will keep the meeting focused
- Allow plenty of time to ask for items to be added to the agenda and circulate well in advance. For information meetings, allow long enough periods for discussion. Patients or parents often need to talk and express their own story, you can offer them a good opportunity but only if you have enough time and if you know how to handle a situation, which, in some cases, can become highly emotional or dramatic.
- Ask for written reports as well as verbal feedback. Organise an evaluation at the end of the meeting (see Toolbox 7.10, page 12).

Booklet 3

Toolbox

OUTREACH MEETINGS, SPECIAL EVENTS, BOOTHS

	Pros	Cons	Most effective use
Special events and booths	• Can achieve high impact with target audience • Can be low cost	• Can require considerable time of staff and/or volunteers	• High impact or interaction is critical

Asociaciòn Española de Porfiria conducted a survey: the association has been able to identify geographic concentrations of family groups in Spain. This was achieved by sending a letter to 5 or 6 departments of all medium and large hospitals; more than 500 were sent out. The objective was to identify doctors who had treated porphyria; about 12 doctors responded.
As a result, the association which started off with

3 or 4 people grew to 26 in the first year, and now has about 100 members.

Good practice:
Wait for the patient to approach the group; just make it known that the group is there and available.
Partnering with another well-known group to raise awareness.

Virtual communities 2.2.5.

Access to "virtual" or online communities is available through the Internet. Through these, people with shared interests can overcome time, cost and distance

to communicate with each other. Virtual communities are an ideal way for people with disabling conditions and rare disorders to talk to each other.

How do they work?

- Different communities offer different features:
  - E-mail lists
  - Discussion boards
  - Polls
  - Live chat rooms
  - Review pages
  - Group areas
  - Personal profiles
- Normally users must register for membership before being allowed to join the community and contribute.
- If you are setting up a virtual community, make sure that users agree to your 'acceptable use' policy.
- Some communities are moderated before any contribution is published; a trusted party must check it meets community standards for decency and legality.

Internet Forums are lists people can join to discuss a subject of common interest. It can be organised with a Forum master. For example, people affected with a rare disease like Xeroderma Pigmentosum and speaking Dutch only can create a Forum where they will exchange messages in their own language.

In the US, **ACOR** (http://www.acor.org), is a non-profit organisation that offers access to mailing lists that provide support, information, and community to everyone affected by cancer and related disorders.

What are the benefits and the concerns?

Online communities can bring many benefits:
- Users will spend longer at your site and return more frequently
- They can be a low cost way of sharing and archiving information
- Existing networks can be enhanced by an online presence
- You gain an awareness of the real needs and interests of your users because they are given the opportunity to talk amongst themselves.

But: How should misleading information disseminated on a discussion forum (or web) be controlled? How should information exchanged in real time be validated/checked (see Toolbox 7.11, page 13)?

	Pros	Cons	Most effective use
Web forums	• Potential for dramatic portrayal of your programme • High impact • Can target public • Longer message possible	• Expensive to produce and distribute • Requires equipment	• Classroom • Seminars • Messages require high-impact visuals • Supplement speech

Recommendations

- All publicly displayed messages are limited to the most appropriate language for your group.
- Members may not use the Forum for commercial gain.
- Members should not use the "Report this thread to a moderator" feature for the sole purpose of getting a staff member to read or reply to the thread.
- Control of cross-posting (people registering with numerous lists in order to disseminate commercial ads or to infiltrate the Forum)
- Consider the possibility of asking IT students or graduates from IT schools or faculties to initiate the creation of a website, or to help maintain it.

	Pros	Cons	Most effective use
Videotapes	• Potential for dramatic portrayal of your programme • High impact • Can target public • Longer message possible	• Expensive to produce and distribute • Requires equipment	• Classroom • Seminars • Messages require high-impact visuals • Supplement speech
Diaporama[7]	• Potential for dramatic portrayal of your programme • Ease of use • Ease of updating	• Training needed • Requires communication skills • Usually limited to 15 minutes • 1 minute per slide	• Classroom • Seminars • Conferences • Video conferences
CD ROMs	• Ease of use • Popular • Easy to disseminate • Longer message possible • Multi-media	• High development cost • "Encyclopaedic" effort	• Home • Training at school • Office use • Seminars

	Pros	Cons	Most effective use
Radio advertising / radio show	• Control of message • May secure free public service announcement (long shot) • Stations have defined audiences • Can have high impact	• No visual image • Need quality taped message (advertisement) • Expensive (advertisement) • Generally no immediate feedback • Message must be short (advertisement)	• For high impact • Simple message • Refer listener to sources "look us up in the phone book or on the Internet"
TV advertising / TV show	• Same as radio but also provides visual images	• Need quality production • Expensive (advertisement) • Generally no immediate feedback	• For high impact • Simple message • Refer viewer to sources "look us up in the phone book or on the Internet"

[7]
e.g. Power Point® presentations for PCs or iView® for Mac

ACKNOWLEDGMENTS

This manual is intended for the creation or the development of information services in the field of rare diseases, with particular emphasis on the quality of information, the access to it, and its appropriate delivery. Information services include classical tools (printed materials and brochures, one-to-one counselling, meetings) as well as tools derived from new technologies (Internet websites, virtual forums, electronic documents), and intermediate services (classical and requiring more and more new technologies) such as phone lines.

Information in the field of rare diseases is primarily intended for people who are affected by a rare disease or a rare disability, their families and relatives, and also for a broader audience among health professionals and the general public.

Patients' groups that are already providing information services will benefit from this manual as they can compare their practices with those that counterpart organisations have validated elsewhere.

This manual is organised into three booklets:

1.

Booklet 1 :
Preparing
the group
and delivering
information

2.

Booklet 2 :
Structuring,
organising,
and managing
the group

3.

Booklet 3 :
Toolbox and
annexes
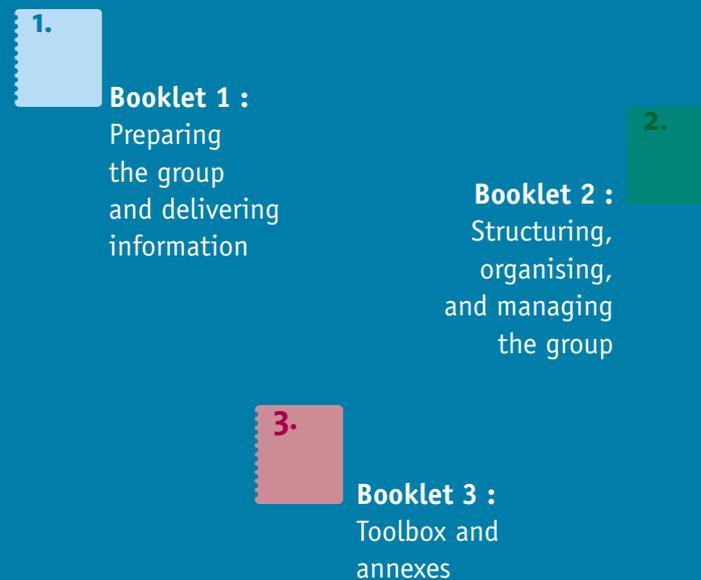
and is one of the achievements of a project supported by the Rare Diseases Programme of Directorate C: "Public Health and Risk Assessment" of the European Commission, and Association Française contre les Myopathies.

More information is available on: www.eurordis.org and www.europa.eu.int/comm/health