EURORDIS
European Organisation for Rare Diseases

Information services for rare diseases

A manual to guide their creation and development

Booklet 3

Toolbox and annexes

AFM | TÉLÉTHON

European Commission

Table of contents

7. Toolbox

7.1. Guidelines for organisations providing information on rare diseases

Preamble

All people, irrespective of race, creed or nationality, should be entitled to a high standard of relevant health care. The highest standards and ethics in the practice of information service should be promoted.

Access to information is a fundamental right, whether the disease is common or rare. Information on rare diseases is one of the most important services that patient groups can provide. This is specifically because people with rare diseases feel isolated by the rarity of the condition affecting them or their family and the additional issues raised by the genetic cause of most rare diseases.

It is also because of barriers that exist in accessing appropriate information on rare diseases that is validated and understandable. There is confusion because many rare diseases are complex syndromes with several definitions and synonyms, which isolates affected people even more.

Rare diseases in Europe represent[1]:

- 5 to 6% of EU population (27 000 000 people after enlargement)
- 6000 to 7000 or even more different diseases.
- A very heterogeneous population with most of patients' groups representing a few tens to a few hundreds of people.
- 80% are of genetic origin.
- They cause disability (44% with mobility impairment), disfigurement (37%) and are a source of discrimination and questions, not only for disabled children facing the world and society, but also for disabled adults with unaffected children.
- They are chronic; they represent 10% of all diseases and are a leading cause of death among young people (35% mortality prior to 1 year of age, 12% between 5 and 15 years of age).

No diagnosis exists for about half of the affected people.

[1] Orphanet 2003

Introduction

Patient driven groups are an unparalleled source of information on rare diseases. They have developed an expertise that is unique and which should be exploited to the full, provided they adhere to the good practices which have been identified and are used by existing groups throughout Europe.

It is always the responsibility of the information service to have high quality information adapted to the needs of the enquirer whatever their reason may be for contacting the service. In providing information, services should always act with respect and empathy.

These recommendations are intended as a guide to recognised good practice and it is hoped readers will make every effort to include that good practice within the information service being developed or reviewed. The information provided is based on the experience of patients. It is recognised that this will be dictated, to some extent, by available resources, and whether the service is delivered by volunteers or paid staff. However there are certain core values that should be practised regardless of size, maturity and resources.

They apply universally, for small groups as well as larger ones, and they constitute long term goals to be achieved. Their implementation should reflect the cultural, political, scope and resources background of each group. Finally information is just one of the many services patients' organisations can provide.

Organisational principles

Patients' expertise:
Recognise the importance of patients and families as a source of information, expertise and empathy. Ensure that services will involve people with rare diseases at all levels of corporate governance and service development where possible.

Inclusiveness:
Recognise the value of family and carers and include them where appropriate, as people affected with a rare disease may have physical limitations, or may suffer from neurological impairment. There should be no distinction among members, whether patients or not.

Accessibility:
Provide information services in settings that are accessible and ensure confidentiality. Severe disabilities are common features of rare diseases. Whenever possible, these services should be free of charge for people with rare diseases and their families.

Sensitivity:
Ensure appropriate and effective services by involving people who reflect the voices of users and carers, as experts in defining their own wishes and needs. Among wishes and needs, questions on genetic inheritance are identified as a very frequent need, as a large majority of rare diseases are of genetic origin.

Human resources obligations:
Deliver an information service by staff, whether voluntary or salaried, who are supported, well resourced and accountable.

Advisory expert committee:
As information on rare diseases is most often sparse and from limited sources, establish an advisory expert committee with experts to whom you may refer social, medical or scientific questions (social workers, lawyers, clinicians and fundamental research scientists). Such a committee could include geneticists when appropriate.

Ethical principles

Confidentiality and use of information:
Respect data confidentiality at all times and personal anonymity unless otherwise directed in writing by the individual concerned. Ensure that data collected always has a purpose and is used and recorded accordingly. Any data for statistical research or evidence purposes should only be disseminated to a larger audience if anonymous, and following consent.

Loyalty:
Ensure that the operator's primary loyalty is to the person to whom they are delivering information, and always in a manner that protects confidentiality.

Anti-discrimination rules:
Consider any person without distinction and prevent discrimination in terms of social situation, education, religion, gender, sexuality, ethnic or geographical origin. Services should be accessible to people with rare diseases of all cultures, beliefs, ethnic and linguistic backgrounds.

Conflicts of interest:
Strive to be independent, autonomous and minimise conflicts of interest.

Sign-posting:
Rare diseases have a major impact on everyday life and not only on patient's health. Have in mind the organisation's limits and make reasonable efforts to offer multi-disciplinary approaches on medical and paramedical subjects, legal and political aspects, social law, ethics, finances… Know to whom enquiries should be referred.

Objectivity:
Ensure that advice remains objective and non judgemental.

Procedural principles

Goals: to provide validated, up-to-date and understandable information on all aspects of the disease to those affected, their families, and the professionals working with them. How to get there:

Field of expertise and diagnosis check:
Define the particular area of expertise unique to the information service. Rare diseases are often complex syndromes with various definitions and synonyms. An enquirer may be calling in the absence of an exact diagnosis, or to obtain information on an already confirmed diagnosis. As rare diseases and syndromes have various names and synonyms, it is crucial to verify the enquirer is contacting the appropriate service.

Complementary role:
Ensure that the information service only consists of explanation, translation into an understandable language and complementary information. The service does not intend to make a diagnosis or give medical advice.

Validation:
Revisit information regularly and check its validity systematically.

Impact of information:
Be aware that information may be interpreted differently by people according to their emotional state, education and experience. Adjust your approach accordingly, being truthful without causing alarm and letting the enquirer set the pace at which information is given. Prognosis or progression of a rare disease is often severe.

Continuous education:
Keep track of medical knowledge and medical progress, train volunteers and staff in a continuous manner.

Isolated people:
Facilitate contacts between isolated people; establish structured channels of information for very rare diseases.

Communication skills:
Ensure that the enquirer is the centre of attention by demonstrating high communication skills, setting aside personal issues and allowing the enquiry to take as much time as is needed.

Clarity:
Ensure that all methods in which information is delivered (information tools) are constantly monitored for accuracy, clarity and accessibility in terms of content, format and appearance.

7.2. Guidelines on how to start a group

See Contact A Family (CAF) in Great Britain.
Contact a Family: 209-211 City Road, London EC1V 1JN
Tel.: + 44 20 7608 8700 - Fax: + 44 20 7608 8701

7.3. Action plan

Action plans are the specific means by which objectives are accomplished. They incorporate five factors:

1. The specific steps or actions necessary to accomplish the objective it supports.
2. The person who will be held responsible for seeing that each step or action is completed.
3. When these steps or actions are to be carried out.
4. The resources that need to be allocated in order to carry out each step or action.
5. The feedback mechanism needed to be able to track the progress of a step or action and to know when it has been completed.

Action plans identify the resource requirements necessary to accomplish an objective. When all action plans are viewed together, management can determine how many objectives they can actually accomplish over a given period of time. If sufficient resources are not available, more must be found and allocated, and/or the objectives must be changed. Decisions in this area may be facilitated by the objective prioritisation process. It is far better to modify an objective to a point that it can be accomplished than to leave unrealistic expectations in the plan.

Name of action:

Item	Description
Responsibility	The person responsible for the execution of the action plan for this objective
Objective	A statement of the objective as it appears in your strategic plan
Completion Date	The date that the objective will be attained or the action plan completed
Revenue Impact	The impact the accomplishment of the objective will have on the organisation's revenue
Cost Impact	The costs attributed to accomplishing the objective, either including or excluding payroll
Prepared By	The person who prepared the action plan
Action Steps	The details for accomplishing the plan

Action Steps	
Step	a brief description of the task to be completed
Schedule	the step's start and finish dates
Accountability	the person responsible for the step and the person who will provide support
Resources	staff hours and amount of euros (or local currency) required for the step
Completion Indicator	the tangible action, event, or product that defines when the step has been completed

Example: to organise a seminar
OBJECTIVE : Information sharing COMPLETION DATE: 10/10/05

Host a «State of the Art» session at the 2005 European Conference on Rare Diseases featuring the latest information on metabolic diseases.

Task	Description	Due Date	Respon-sibility	Support	Resources	Completion Indicator
1	Establish a Meetings and Membership Committee	1/11/04	Meetings chair	Working group	-	Committee formed
2	Contact National Alliance in charge of programme	10/10/04	President	-	€ 500 Deposit	Room Reserved
3	Identify potential speakers and/or activities	17/10/04	President	Working group	-	Target list defined
4	Secure speaker commitments	17/06/05	President	Working group	Phone calls	Speaker acceptances
5	Obtain Board approval to conduct this event	30/10/04	President	-	-	Board Motion
6	Identify possib auxiliary activities (Special bread display, samples, wheel chair access, refreshments, materials...)	1/06/05	Meetings chair	Working group	€ 500	Report to President
7	Develop event announcement plan (Advertisements/ Invitation/ Membership notice/ other?)	1/03/05	President	Conference organising committee, Working group and Meetings Chair	Volunteer time	Prioritised and costed list
8	Execute Announcement Plan	1/03/05 to 1/08/05	President	Working group	€ 1500	Invitations printed, Advertisements placed
9	Co-ordinate speakers, facilities and activities	1/08/05 to 10/10/05	Meetings chair	Working group	€ 1000	Successful Event
10	Thank you to speakers and key support staff	17/10/05	Meetings chair	-	-	Letters issued

7.4. Financial aspects of the business plan

Costs of getting your service up and running go into the start up expenses category. These expenses may include:

- service registration fees
- service licensing and permits
- starting inventory
- rent deposits
- down payments on property
- down payments on equipment
- utility set up fees

This is just a sampling of start up expenses; your own list will probably expand as soon as you start writing them down.

Operating expenses are the costs of keeping your service running. Think of these as the things you are going to have to pay each month. Your list of operating expenses may include:

- salaries (staff salaries)
- rent or mortage payments
- telecommunications
- utilities
- raw materials
- storage
- distribution
- promotion
- loan payments
- office supplies
- maintenance

7.5. Example of a position title for a member of the board of directors

Position Title: Member, Board of Directors.

Function: Provide governance to the service, represent it to the community, and accept the ultimate legal authority for it. Duties:

Planning

- Approve the organisation's philosophy and review management's performance in achieving it.
- Annually assess the environment and approve the organisation's strategy in relation to it.
- Annually review and approve the organisation's plans for funding its strategy.
- Annually review and approve the budget.
- Approve major policies.

Organisation

- Elect, monitor, appraise, advise, support, reward, and, when necessary, change top management.
- Be assured that management succession is properly being provided.
- Be assured that the status of organisational strength and manpower planning is equal to the requirements of the long range goals.
- Approve appropriate compensation and benefit policies and practices.
- Propose a slate of directors to members and fill vacancies as needed.
- Annually approve the Performance Review of the Chief Executive Officer and establish his/her compensation based on recommendations of the Personnel Committee and Chairman of the Board.
- Determine eligibility for and appoint Board Committees in response to recommendations of the Nominating Committee.
- Annually review the performance of the Board and take steps to improve its performance.

Operations

- Review the results achieved by management as compared with the organisation's philosophy, annual and long range goals, and the performance of similar organisations.
- Be certain that the financial structure is adequate for its current needs and its long-term strategy.
- Provide candid and constructive criticism, advice, and comments.
- Approve major actions, such as capital expenditures and major programme and service changes.

Audit

- Be assured that the Board and its committees are adequately and currently informed - through reports and other methods - of the condition of the organisation and its operations.
- Be assured that published reports properly reflect the operating results and financial condition of the organisation.
- Ascertain that management has established appropriate policies to define and identify conflicts of interest throughout the organisation, and is diligently administering and enforcing those policies.
- Appoint independent auditors subject to approval by members.
- Review compliance with relevant material laws affecting the Institution

7.6. Three tips for recruiting New Board Members[2]

1. Form a "One-Meeting Nominating Committee". Draw up a list of ten to twenty well-connected people of the sort you would want on the board but who you suspect wouldn't join, (but who might know someone who would be a good board member.) Call those ten -twenty people and ask them to come to a one-meeting committee over lunch. Tell them that at the lunch they will be told more about the service and what it's looking for in board members. At the end of lunch they will be asked simply for the name of one person they think would be a good board member. The day after the lunch call up each of the nominees and begin by explaining who nominated them.
2. Ask the executive director or the volunteer coordinator if there are two or three hands-on volunteers who would make good board members. Hands-on volunteers, such as support group facilitators, practical life support volunteers, meal preparers, newsletter volunteers, and others bring both demonstrated commitment and an intimate knowledge of the service's strengths and weaknesses. Volunteers, donors and clients should be the first place you look. You do not have to "sell" the service - they know it already!
3. Pick four local groups where you do not know anyone. Ask each officer to call one of the four local groups and ask to have coffee with the board president or the executive director. Over coffee suggest that your two groups recommend "retiring" board members to each other as a way of establishing organisational links and strengthening ties among groups.

7.7. Board relations: A user's Guide to Effective Board Retreats[3]

The probability of an effective board retreat will greatly increase if you work the following factors into your retreat plans.

1. List the desired outcomes. An outcome can be a plan, a mission statement or a policy. Have such outcomes in mind as you develop the retreat agenda.
2. Include staff in the retreat. The number included depends on your service. A general rule is that you do not want the staff to outnumber the board members.
3. Use a facilitator. You -- or any staff or board member -- may be a gifted and experienced facilitator, but your title will get in the way of effective interaction.
4. Break up the work sessions. Though the board is there to think and work, do not wear people out. Give people breaks, and you will get more out of them.
5. Document the various discussions. Ask the facilitator to write the key points on a flip chart while a scribe takes down all the details. Develop and distribute a report to all retreat participants.
6. Stick to the issues at hand. If you are having a retreat to discuss long-range plans, set a rule at the beginning of the retreat that you will not allow discussion of current events unless they have true long-term implications.
7. Encourage everyone to participate. The worst thing that can happen at a retreat is for someone to say nothing. Work with your facilitator to make sure that everyone is politely but firmly forced to add something to the discussion.

2 BOARD CAFÉ - The Electronic Newsletter Exclusively for Members of Nonprofits Boards of Directors

3 Peter C. Brinckerhoff writing in Association Management,

7.8. Enquiry form template sample (adapted from FEDER, Spain)

DATE
REGISTRATION#

Enquirer	Enquiry related	Action
Personal data Name: .... Birth date: .... City: ..... Post code: ..... Telephone: ..... Email:	To disease ☐ To contact with other patients ☐ To treatment centres ☐ Other	Sign posted to specific group ☐ Yes ☐ No Which one ....
Disease Name .... Disease description	Content of enquiry .... Motive .... Information sent	Affected person ☐ Family ☐ Professional ☐ Heard about the service through: Media ☐ Brochure ☐ Advised by Internet ☐ Other ☐
Comments		Contacted by: Telephone ☐ Fax ☐ Mail ☐ E-mail ☐ Visit ☐

7.9. An example of procedures for information service operators: FEDER

PROTOCOL PERFORMANCE S.I.O
Information service and Orientation
Document type: Internal - Technical
Elaborated for: -. Social worker

Introduction
The present document exposes basic rules, both theoretical and practical, of the information service:
1. What does the service consist of?
2. Users
3. Purposes
4. Rules of operation
5. Current location and relationship with FEDER

1. What does the service consist of?
The service is aiming at facilitating access to information and existent resources on rare diseases:
- Information on the diseases.
- Directories (associations, centres, specialised doctors and experts...).
- Exchange of experience/information between people affected by the same disease or syndrome.
- Encouragement to create support groups.
- Encouragement of families/affected people to become members of a patients' association.

2. Users.
- Affected people and/or their families
- Related health professionals, and also social workers, psychologists, nurses...
- Entities, associations and related and/or interested parties

3. Purposes
Information provided does not substitute to medical advice and information provided by treating physician.
- No individual diagnostic orientation is given: if an enquirer explains symptoms and asks the service for a possible diagnosis, the only possible response is to refer the enquirer to a medical opinion (in liaison with the service experts, or using the directory of reference centres for diagnosis)
- Prescription of treatments (including diets, medications...): similarly, if an enquirer with a known diagnosis asks what medicinal products he/she could be treated with, the only possible response is to refer the enquirer to a medical opinion (in liaison with the service experts, or using the directory of reference centres for diagnosis)

4. Rules of operation
Bases on what precedes, tasks of service operators should be:
For direct enquiries:
- Reception of the first demand, by all possible means available, usually electronic mail and telephone
- Creating a file - see ANNEXED PROTOCOL below
- If no information is available about a disease, then decision is made to start searching for information
- Sign-posting: refer the call to another organisation or agency or expert if necessary
- Response: by referring the enquiry to specialised associations, centres and/or reference experts
- To propose contact with other affected people and/or group formed
- To propose a follow-up call or the possibility to send e-mail/letter
- Filing the enquiry form. Personal data, data about the enquiry are captured in a database in electronic format, being upgraded with new files and/or data on a daily basis. Written form files are classified manually

Indirect enquiries:
- Enquiry sent to FEDER from another association, member or not member of FEDER
- To establish contact with this organisation
- Then proceed as described above

ANNEXED PROTOCOL
1. Technical aspects.
Collection of data: strictly necessary data to be recorded, i.e.:
- Contact details
- Complete name of the disease. Synonyms can be listed when used with no distinction (e.g. Syndrome of Strumpell Lorraine or Family Spastic Paraparesia)
- If the enquirer is not the affected person, name of patient, its age and the relationship with the enquirer are needed
- In some circumstances, clinical information can be recorded (e.g. diagnostic centre, treatment centre, referring health care professionals, suspected diagnosis)
- Action initiated must be recorded, as well as response given
- When person is referred to another patient or a family, name of contact family/contact person is recorded

2. Sign posting.
If the enquirer is invited to contact other organisations:
- ALWAYS give exhaustive list of other organisations (if appropriate)
- ALWAYS consult the entire listing of associations that are members of FEDER
- Record the names of the organisations where the enquirer is referred to

In case the enquiry relates to a given disease for the first time:
- Proceed by all possible means to the search of available information
- Send the information you have gathered to the person in charge of archiving new information
- If you identify a new organisation, update the database of disease organisations. The service will contact this new organisation to explain FEDER activities and our services

3. Enquiries from other countries.
- refer to an existing Alliance in this country
- else, if no Alliance exists or if the service has no contact in this country on the disease, proceed as if the enquiry would originate from Spain

7.10. Evaluation form for a meeting

Meeting : ..... Date : .....

Please give us your opinion of today's meeting. Your comments will help us improve future sessions. Please circle the number that corresponds with your level of agreement with each statement, with 1 = strongly agree, 2 = agree, 3 = disagree, and 4 = strongly disagree.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. The meeting was well organised	1	2	3	4
2 The meeting duration was just the right length	1	2	3	4
3. The content was too elementary	1	2	3	4
4. Presentations were clear and understandable	1	2	3	4
5. The moderator/chair was well prepared	1	2	3	4
6. The moderator/chair encouraged questions	1	2	3	4
7. The handouts were useful	1	2	3	4
8. The examples/case study helped clarify the subject	1	2	3	4
9. I learned information and made contacts that will help my daily work	1	2	3	4

OPTIONAL: The core evaluation questions can be followed by a section for specific questions, such as:

I now understand the difference between _database X_ and _database Y__	1	2	3	4
I feel comfortable searching _blank_	1	2	3	4
I have learned how to locate (citations, articles, electronic journals, etc...)	1	2	3	4
I feel this meeting was well worth my time	1	2	3	4

Please comment

Was there any aspect you were interested in, that was not covered in today's meeting?
How could the meeting have been better or more helpful?
Any other comments?

.....
.....
.....
.....
.....

Thank you very much!
Please return your completed evaluation form to .....

Self-evaluation form for volunteer and staff 7.11.

Date of Appointment to Current position/Job:
.....
Evaluation period from: .....
To: .....
Date of Evaluation: .....

1. Job Description

a. The volunteer or the employee should review again his/her job description to be certain that there is a clear understanding of responsibilities of the job. Identify changes that have occurred in the position.

b. Did I meet the responsibilities of the job as defined by the job description? Rate your performance on each duty on the job description. (Numbers below correspond to the numbered duties on the job description. Add additional numbers as needed.)

The rating factors are as follows:

(O) Outstanding (Indicates exceptional performance)
(C) Commendable (Performance is beyond normal requirements and competence)
(E) Effective (fulfils the normal job requirements with some strong points)
(N) Need Improvement (Performance is below job requirements, but improvement is anticipated)
(U) Unsatisfactory (Job performance must be improved substantially to be acceptable)

2. Evaluation of Performance

Consider each of the performance criterion below and indicate the rating factor that most nearly describes your performance during the evaluation period.

a. Communications: (oral and written) o c e n u
Comments: .....
.....

B. Job Knowledge: o c e n u
Comments: .....
.....

c. Organisation and Planning: o c e n u
Comments: .....
.....

d. Leadership and Supervision: o c e n u
Comments: .....
.....

e. Dependability: o c e n u
Comments: .....

f. Initiative: o c e n u
Comments: .....
.....

g. Problem Solving Ability: o c e n u
Comments: .....
.....

h. Adaptability: o c e n u
Comments: .....
.....

i. Professional Attitude: o c e n u
Comments: .....
.....

j. Productivity: o c e n u
Comments: .....
.....

k. Relationship with Others: o c e n u
Comments: .....
.....

3. Achievement of Goals

Please refer to the goals and objectives set at the time of the last performance evaluation and comment on each of the following:
Were goals for this period fully achieved?
Comments: .....
.....
.....

Were significant accomplishments achieved that were not stated goals?
Comments: .....
.....
.....

If some goals were not achieved, or were not achieved in a timely fashion, explain the reason.
Comments: .....
.....
.....

4. Overall Rating (a short statement of your total evaluation):

.....
.....

5. Future Goals

Establish future long range goals and shorter term objectives with projected dates of achievement. Where possible describe specific objectives with measurable outcomes. Progress toward these goals and objectives will be assessed in the next performance evaluation.

Date of next regular evaluation: .....

7.12. Some common rules on how to best use electronic communication

- Users need to think carefully about the amount of personal information they give. In chat rooms, use an e-mail address you reserve for that purpose
- Remember that there will be a range of different views presented ranging from orthodox to complementary treatments
- People with the same disorder may be affected differently
- If children are to use chat rooms, either generally, or about a specific disorder, check these websites that can alert you to pitfalls:
  - www.thinkuknow.co.uk for children to learn about Internet safety
  - www.chatdanger.com contains sections for parents, youngsters, schools & general background safety on the Internet
  - www.childnet-int.org International Internet *safety* site

These three sites give instructions on how to insert a Safety on the Internet banner on your website.

For families with children and teenagers the AOL Internet Service Provider (ISP) includes safety provision which places the limits on the use of the Internet decided by parents. For those not using AOL, Net Nanny (www.netnanny.com) and Cyber Patrol (www.cyberpatrol.com) software will carry out the same function.

One property of electronic mail is that it is so easy to disseminate a message to so many people. Many ethical rules try to avoid the problems which this may cause, e.g.:

- *think* before you write
- *keep to the topic* of a group discussion
- *begin with the most important thing* you have to say (so that those not interested can skip the rest)
- *never write a message when you are angry*, etc.

The fact that you can wait a few hours to calm down before you write a message is an advantage electronic mail compared to face-to-face meetings.

- it happens that a message written to a small group is forwarded without permission from the author to a much larger group. Sometimes, the author of the message does not like this. Because of this, a common ethical rule is that you *should not resend texts to larger and more open groups without permission from the author.* This, like most ethical rules, should not be absolute. It is easy to see that in a particular case, the forwarding of a message will not be controversial: or that there may be a large common interest in something which has occurred in a small group that should be known by a larger group. Copying texts written by others is also controlled by copyright laws.

General courtesy rules of *friendliness and consideration* may be more important in electronic mail than in face-to-face communication, since you cannot, for example, immediately see a negative reaction and correct and clarify what you mean.

Ethics and Language

Face-to-face communication involves body language, facial inflections, and nuances of voice. Such tools give important emotional signals in association with what you are explicitly saying for example, to clarify that you were ironic. Because written communication lacks these tools, serious misunderstandings can occur. To avoid this, special punctuation (so-called « smileys ») is sometimes used in electronic mail to indicate that what you are saying is not to be interpreted at face value. Common punctuation is, for example, ":-)" (which looks like a smiling face if you turn it 90 degrees).

There are also other special syntactical conventions used in electronic mail. Many electronic mail networks are not capable of forwarding underscored, **bold**, or *italic* text. Because of this, a common convention is to write one or more asterisks around a word you want to stress. Another common convention is to put " >" in front of quotations, usually at the beginning of a line. For example,

Andersen writes something very **important**:
> Body language can sometimes be replaced
> by special symbols,
> but sometimes people may overstep the mark.

Some e-mail communities also adopt a modified language for use in e-mail. Such language can, of course, be a barrier to new e-mail users. Here are some examples of special terms in such a modified language:

ASAP	as soon as possible
BTW	by the way
IOW	in other words
FYI	for your information
IMHO	in my humble opinion
RSN	real soon now (which may be a long time coming)
FAQ	frequently asked question
OBO	our best offer
2	'to'. For example, 'F2F' or 'face2face' as abbreviations for 'face to face'
:-)	this is a joke, not to be taken seriously
:-(	I am unhappy
;-)	winking, teasing, flirting

What are the costs?

Software and hosting can be expensive, especially if you require many features.

Moderation is very labour-intensive, but mature communities can often be self-policing.

However, the legal ramifications if anything goes wrong can be immense.

Where can I find examples?

- www.acor.orgThe heart of ACOR is a large collection of cancer-related Internet mailing lists, which delivered about 1 800 000 e-mail messages weekly to subscribers. In addition to supporting the mailing lists, ACOR develops and hosts state-of-the-art Internet-based knowledge systems that allow the public to find and use credible information relevant to their illness.
- www.mswebpals.org Julie's Joint 'people with Multiple Sclerosis supporting each other'. This site has been created by an affected person who is a professional expert on website quality.
- A number of support organisations cited in the Contact a Family Directory (www.cafamily.org.uk) have established bulletin boards, forums and chat rooms. These include:
- www.jtsma.org.uk Jennifer Trust for Spinal Muscular Atrophy (JTSMA)
- www.marfan.org.uk Marfan Association
- www.rarechromo.org Unique – the Rare Chromosome Support Group

How do we set one up?

- Define your goal and audience
- Identify which features serve your purpose and audience
- Think about how you want to host or facilitate your community
- Build it
- Draw in the members by seeding discussions, attracting links and posting in other communities
- Nurture

A good starting point is www.fullcirc.com/community/communitymanual.htm. This site has a comprehensive range of information including:

- www.fullcirc.com/community/purposecheck.htm A check list to guide community builders.
- http://builder.cnet.com/webbuilding/0-7391.html advice on what kind of virtual community to build
- http://groups.yahoo.com. Very helpful site listing a huge number of groups and easy instructions for starting a new one.

Your organisation: the public face 7.13.

Patients' organisations are not casting agencies. Direct testimonies from affected people help communicating the disease to the general public. Organisations with spoke-people can respond to such solicitations, but then training in communication may be required.

National alliances should be go-betweens with the media as they represent more patients.

Facing the media: some tips

Always be open and direct, in particular with journalists. For instance, ask them what you need to tell them for them to publish your story. Do not be shy. It helps to get training from a journalist on how to liaise with journalists and how to conduct a press campaign.

The communication campaign should develop a press list, including contact information for the various forms of media that serve the target audience. A press list should contain the newspaper, television, and radio outlets in the area as well as their news deadlines. The characteristics of the audience for each media source are important to know. In addition to the press information packet, there are a number of means of developing contacts with the press and getting attention in the media.

Who are you talking to?

Who is your audience? What is the readership of the reporter's newspaper? Address the fears and concerns of your audience?

Be prepared.

Ask the reporter, before the interview, for a rough outline of what sort of story he or she plans to do. Work out your key points.

And be prepared for the worst possible questions.

Never lose your cool. If you do not know the answer to a question, do not try to fudge it. Admit you do not know, undertake to find out, and then pass on the information.

Be reliable.

Return phone calls. Answer e-mails.

Give examples.

Do not ramble on about broad generalities. Be specific. Reporters and their readers want to know what you are talking about. Readers relate to concrete examples.

Be honest.

Your credibility is at stake, and once that is lost, you will probably never recover it. Talk about your

problems; do not shy way from them. But also talk about what is being done to resolve them.

Speak clearly.
Make sure the reporter understands what you are telling him or her. Explain things.

Do not ever make a reporter feel he or she has asked a stupid question.
It is better that a reporter asks, than feels too intimidated to ask a "stupid" question and then gets it wrong in the story.

When editing a press release

A news release is a one- to two-page (400 to 800 words) description of an event, programme, or activity. Some newspapers use news releases without changing them. Sometimes, reporters attend the event or may follow up to write a story. News releases should include the following: 1) one or two quotes from leaders; 2) facts: who, what, where, when, why and how; and 3) contact information for the spokesperson.

Find out to whom to direct the release.
If you are writing about health, then send the release to the health editor, not the economics editor and not "The Editor". Call the newspaper beforehand to find out the person name, and how to spell it.

Be interesting.
Find a "hook" for your release – something that is new, different, and unique. Remember that news is generally something out of the ordinary.

Be concise.
Get straight to the point. Do not hide your key point in paragraph 10 on page three. The reporter or editor will have stopped reading long before that, and gone on to the next press release on his or her large pile. Yours will now be in the garbage bin. Put your most important information at the top of the release.

Do not oversell.
Do not try ²to dress your message in a lot of flowerily language about a company or product. That just adds to the editor's workload. If, by some odd chance, they still wish to use such a release, they will have to spend valuable time sifting out the PR plugs.

Make them literate and easy to read.
Bad grammar and spelling errors irritate the editor or reporter. The story is not likely to be used.

Check facts.
It is amazing to see how many press releases contain incorrect figures and names. A release from you may be used once, but never again.

Avoid jargon.
If you simply have to use it, then explain, clearly, what it means. Jargon does not show that you are clever, just insensitive. A basic rule for reporters is that they assume their readers know nothing of the background of a story – the same rule applies to you.

Explain acronyms.
Do not assume the editor or reader knows what PMA, or whatever, stands for. Save him or her from the effort of a phone call, and prevent your release landing up on a pending file. Pending means "spiked" – remember, yours is one of 50 or so to reach the editor or reporter.

Offer photographs or illustrations.
A story with an illustration has a much higher chance of being used, and of being used well.

Follow the release with one polite and brief phone call.
Do not bug the editor about publication.

Give examples.
Specifics, to which readers can relate, will help your story get into the paper.

Know the audience.
Target your release for specific newspaper readership.

Offer exclusivity.
This will help to get your release used. Offer it to a selected publication first, and tell them you will release it to other media on a specified date.

Press information package

One important tool for a media campaign is the press information packet. It should contain basic background material on the organisation. Factual information can be used to educate reporters on the issues and interest them in a story. Whether or not an campaign needs a press information packet depends on the size of the campaign. A small campaign may not wish to spend time and effort to create a press packet, but may reach out to the media in other ways. A large campaign, which deals with many different members of the media, will find that the packet can save time, attract attention, and provide information and quotable statements.

A packet may include:

- Information about the organisation, including a list of members and the organisation's mission and goals;
- Contact information for the press spokesperson;
- Background data (such as fact sheets) on the rare disease
- Positive press coverage the campaign has received;
- Information on how the proposed programme or policy change will address patients' needs
- Materials that help reporters write a story, such as recent research, quotes from the campaign leadership, and copies of other opinion leaders' speeches or testimony.

Events

Inviting the media to an event already planned is an inexpensive way to generate contacts and publicity. Tell participants in advance that the media will be coming. A spokesperson or liaison should be available to assist members of the press, provide background information, and introduce them to notable people present.

Letters to the editor

Newspapers frequently print letters to the editor that address an issue which has been in the news recently. The letters to the editor section is one of the most frequently read sections of newspapers and is an ideal place to respond to criticism or concerns. Letters should be brief and persuasive, and should use clear facts or quotes from respected opinion leaders. A prominent member of the organisation or community can be asked to write or sign a letter drafted by a member of the campaign.

Television and radio

Many television and radio stations have news as well as discussion shows for current issues. Identify news directors and talk show producers who may be interested in covering the issue. The host of a discussion shows may be interested in dedicating an edition to a suggested issue. "Call-in" radio shows on a relevant topic can provide opportunities for a spokesperson or leader to speak directly to the radio audience.

Working with service providers and suppliers 7.14.

Contract Checklist[4]
This document is intended to provide a list of possible information to include when writing a contract between a buyer and vendor of services and/or products.
Not all items are relevant in all contractual situations. In some situations, other provisions may be appropriate that are not listed below. This document is not intended to substitute for legal advice nor legal wording provided by a competent advisor in the relevant legal jurisdiction.
The information in *italics* is intended to explain the item suggested for possible inclusion in a contract.

Title of Contract
Examples: Software License Agreement, Provision of Internet Services.

Parties to the Agreement
Identifies the full legal names of the provider and the buyer of the service and/or product. Any any abbreviated names (in parentheses after the legal name) these parties use for the purpose of the contract are also identified.

Date of Contract
The date the contract is written.

Subject of Contract
Identifies generally services and/or products being supplied under the contract.

Deliverables
Lists specifically everything the vendor is to deliver to the buyer.

Restrictions
Identifies any limitations in use of the supplied services and/or products (e.g., software can only be installed and used by the buyer on one machine at any given time, with permission to make one back-up copy).

Payment Terms
Explains the frequency, amount and timing of payments to be made by the buyer to the vendor (often upon completion of one or more itemized deliverables).

Confidentiality
Identifies any restrictions on the distribution of information contained in the contract and/or in the deliverables.

Ownership of Intellectual Property
Outlines the ownership of copyright, patents, source code, executable code, documentation, content and all other deliverables supplied under the contract.

Warranties
Explains the duration and nature of the vendor's obligations to the buyer regarding the performance of its deliverables. Also identifies any conditions that may render the warranty null and void and how the buyer is to notify the vendor of warranty issues.

General Provisions
- **Assignment** – Identifies if either party to the contract can transfer the contract, in whole, or in part, to another party, and

4 From apc. org, Association for Progressive Communication

under what conditions (if any).

- **Liability** – Describes what each party is and is not accountable for in case of non-performance or other possible problems. Identifies a maximum value (if used) to limit the amount of liability involved in the contract (often the total value of the contract itself).
- **Indemnification** – An assertion, if applicable, that the vendor will protect the buyer from third party intellectual property rights claims against the buyer for deliverables supplied by the vendor, provided the vendor has the right to substitute alternative deliverables should such a situation arise.
- **Entire Agreement and Amendment** – Explains that the written contract is the only description of the agreement between the vendor and buyer, regardless of what may have been previously stated or written down. Explains the process for updating the contract (often based upon mutual agreement, in writing).
- **Applicable Jurisdiction and Method for Dispute Settlement** – Explains what the relevant legal demarcation is for the governing laws of the contract and describes how disputes will be settled (e.g., by the courts, by mediation, by binding arbitration).
- **Default** – Explains the conditions that, if met, constitute default (or breach of contract) by either party. Specifies the method and timeframe available to the parties of the agreement to take corrective action, failing which the contract shall be considered null and void.
- **Waiver** – An assertion that any delay or partial pursuit by one party of its rights against the other party does not constitute a forfeiture of the right to later seek further or complete remedy or redress to a situation, should the need arise.
- **Severability** – Explains that if any of the provisions of the contract are rendered null and void, all other provisions remain in force.
- **Notices** – Describes how and where the parties shall formally communicate to each other in the event they need to take such action (e.g., all notices shall be deemed to have been received by the other party within five working days if sent by regular mail to the addresses below).

Sign Offs

- **Parties to the Agreement** Formally identifies the legal names of the entities (people, companies, NGO's, etc.) and their representatives (e.g., President, Vice-President, etc.) signing the contract.
- **Date** – Identifies the date the party to the agreement signed the contract.
- **Witness(es)** – Signature of person(s) formally witnessing the signing of the contract.
- **Company Seal** – A place on the contract for a corporate seal to be imprinted (if required).

Annexes 8.

A disease description by CLIMB: Metachromatic Leukodystrophy 8.1.

Other names for this condition are:

- ARSA
- Arylsulphatase A Deficiency
- Cerebroside Sulphatase Deficiency
- Diffuse Cerebral Sclerosis
- Greenfield Disease
- Late-Onset Metachromatic Leukodystrophy
- MLD
- Metachromatic Form of Diffuse Cerebral Sclerosis
- Metachromatic Leukoencephalopathy
- Sulphatide Lipidosis
- Sulphatidosis

This is a disorder where the insulating fatty coverings (myelin sheaths) that surround the nerves in the brain breakdown. This is called cerebral demyelination. This breakdown is due to the accumulation of sulphatide, a fatty substance in the brain. The accumulation of sulphatide is due to a deficiency in an enzyme called arylsulphatase A. There are three forms of this condition infantile, juvenile and adult.

This disorder is inherited from the genes of the parents. For a child to have the condition a gene for the disease must be inherited from both parents, this is called autosomal recessive inheritance.

- The infantile form of this condition has symptoms usually beginning between the age of 6 months and 2 years.
- The juvenile form typically has symptoms appearing between 4 and 10 years of age.
- The adult form has symptoms that arise after the age of 16 years.

The symptoms of this disorder tend to be subtle and appear gradually. In all the different forms the common symptoms include muscle weakness (hypotonia), the loss of ability to co-ordinate movements (ataxia), muscle spasms (rigidity) and the loss of previously acquired physical and mental skills. There may also be some difficulties with speech, deterioration in the vision due to optic atrophy that can lead to blindness, swelling of the abdomen and possibly fits (seizures). As the disease progresses, it can lead to blindness, paralysis and behavioural problems. Adult forms may result in psychological problems.

Treatment for Metachromatic Leukodystrophy is symptomatic and supportive. It aims to relieve symptoms and make the individual as comfortable as possible. The prognosis for individuals with this condition varies depending on the form. Children with the infantile form rarely live into adolescence. With the juvenile form children rarely reach adulthood. Adults who have this disease do not usually reach middle adulthood.

This information is fully sourced and referenced, for more detailed information and references please contact Climb by e-mail, letter or telephone.

Disclaimer

This information about metabolic diseases is provided by Climb and is intended for educational purposes only. It should not be used for diagnostic or treatment purposes. Should you require more detailed information please contact Climb by e-mail (info@climb.org.uk) or by telephone (0800 652 3181). For specific medical information regarding a particular disease or individual please contact your GP or Paediatrician.

Climb accepts no responsibility for any errors or omissions nor does Climb assume any liability of any kind for the content of any information contained within this summary or any use that you may make of it.

8.2. One hierarchy describing levels of evidence for medical facts

Adapted from the Cochrane Collaboration and from Knopman et al. (May 8, 2001) *Neurology*, 56 (9), 1143.

Level	Description	Example
Experimental or class 1	• "Gold standard". Random assignment to and evaluation of intervention and control groups/phases	• Randomised clinical trial
Quasi-experimental or class 2	• Non random assignment to and evaluation of intervention and control groups/phases groups/phases • Well designed study of a narrow spectrum of people with suspected condition • Well designed retrospective study of a broad spectrum of people with established condition • Comparisons with broad spectrum of controls	• Case controlled led studies • Cohort studies • Systematic reviews of observational studies • Quality improvement studies
Non-experimental or class 3	• No clear comparison groups, or non-randomised historical controls • Evidence from retrospective study in which either people with established condition or controls are of a narrow spectrum; blinded evaluation	• Registries and data bases
Class 4	• Any design in which test is not applied in blinded evaluation or evidence provided by expert opinion alone or in descriptive case series	• Group judgments or Expert opinion • Case studies or reports

8.3. Protection of individual data

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

Criteria for making data processing legitimate

Article 7 Member States shall provide that personal data may be processed only if:

(a) the data subject has unambiguously given his consent; or

(b) processing is necessary for the performance of a contract to which the data subject is party or in order to take steps at the request of the data subject prior to entering into a contract; or

(c) processing is necessary for compliance with a legal obligation to which the controller is subject; or

(d) processing is necessary in order to protect the vital interests of the data subject; or

(e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller or in a third party to whom the data are disclosed; or

(f) processing is necessary for the purposes of the legitimate interests pursued by the controller or by the third party or parties to whom the data are disclosed, except where such interests are overridden by the interests for fundamental rights and freedoms of the data subject

8.4. Code of Conduct for medical and health websites

For other languages, connect to:
http://www.hon.ch/index.html

Principle 1 guidelines

Authority

Any medical or health advice provided and hosted on this site will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organisation.

Principle 2 guidelines

Complementarity

The information provided on this site is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician.

Principle 3 guidelines

Confidentiality

Confidentiality of data relating to individual patients and visitors to a medical/health Web site, including their identity, is respected by this Web site. The Web site owners undertake to honour or exceed the legal requirements of medical/health information privacy that apply in the country and state where the Web site and mirror sites are located.

Principle 4 guidelines

Attribution

Where appropriate, information contained on this site will be supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified will be clearly displayed (e.g. at the bottom of the page).

Principle 5 guidelines

Justifiability

Any claims relating to the benefits/performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.

Principle 6 guidelines

Transparency of authorship

The designers of this Web site will seek to provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support. The Webmaster will display his/her E-mail address clearly throughout the Web site.

Principle 7 guidelines

Transparency of sponsorship

Support for this Web site will be clearly identified, including the identities of commercial and non-commercial organisations that have contributed funding, services or material for the site.

Principle 8 guidelines

Honesty in advertising & editorial policy

If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the Web site owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

Sample of Web sites subscribing to HONcode

- E – Cardiologie : http://www.e-cardiologie.com/
- PediatricNeurology.com ADHD e-book : http://www.pediatricneurology.com/
- Groupe de Réflexion sur l'Obésité et le Surpoids : http://www.gros.org/
- DietWatch.com : http://www.dietwatch.com/
- National Institute of Mental Health (NIMH) : http://www.nimh.nih.gov/
- Diabetes123.com : http://www.diabetes123.com/
- Alzheimer Society of Canada - Société Alzheimer du Canada : http://www.alzheimer.ca/
- Association Internationale Ensemble Contre la Douleur : http://www.sans-doubleur.ch/
- Belgian Orthoweb - Belgian Orthopaedics Online : http://www.belgianorthoweb.be/noie.htm
- Orthogate : http://www.orthogate.com
- Beth Israel Deaconess Medical Center : http://www.bih.harvard.edu/
- Centre d'Imagerie Diagnostique – CID: http://www.cid.ch/
- Children with Diabetes: http://www.childrenwithdiabetes.com/
- Diabetes UK: http://www.diabetic.org.uk/
- Doctor's Guide to the Internet: http://www.diabetic.org.uk/
- Drug InfoNet: http://www.druginfonet.com/
- European Health Telematics Observatory (EHTO): http://www.ehto.org/
- FinOHTA - Finnish Office for Health Care Technology Assessment: http://www.stakes.fi/finohta/e/
- GENEtica & CAncro (GENECA): http://www.geneca.it
- Glaxo Wellcome: http://www.glaxowellcome.co.uk
- Haydarpaa Numune Hospital – HNH: http://www.kilim.com.tr/numune/
- HIV Medication Guide: http://www.jag.on.ca/hiv/
- Hospices Cantonaux Lausanne – CHUV: http://www.hospvd.ch/
- Mayo Health O@sis: http://www.mayoclinic.com/
- National Cancer Institute (NCI) - CancerNet database - University of Bonn: http://www.meb.uni-bonn.de/cancernet/cancernet.html
- Servicio de Aparato Digestivo del Hospital Universitario Virgen Macarena: http://www.gastrohvm.arrakis.es/
- TOCOGINECOnet: http://www.tocoginet.com.ar/
- Anestesia in Rete: http://www.salus.it/anest/
- Laboratory for Infectious Diseases - Hvidovre Hospital: http://www.inet.uni2.dk/~mamocell/

8.5. e-Europe action plan

e-Europe Action Plan - Participation for all in the knowledge-based economy

Action	Actor(s)	Deadline
Policies to avoid info-exclusion will be more effectively co-ordinated at European level through benchmarking of performance and exchange of best practice between Member States	Member States, European Commission	end 2001
Publication of «Design for all» standards for accessibility of information technology products, in particular to improve the employability and social inclusion of people with special needs	European Commission, Private Sector	end 2002
Review relevant legislation and standards to ensure conformity with accessibility principles	Member States, European Commission	end 2002
Adoption of the Web Accessibility Initiative (WAI) guidelines for public websites	European Commission, Member States	end 2001
Ensure the establishment and networking of national centres of excellence in design-for-all and create recommendations for a European curriculum for designers and engineers	European Commission, Member States	end 2002

Health online

Health services in all Member States are large, expensive and complex sectors to administrate. A collaborative objective is to develop an infrastructure of user friendly, validated and interoperable systems for health education, disease prevention and medical care.

Many of the tools for the building of such an infrastructure exist, however efforts are needed at Member State level to move towards the implementation of the infrastructure in a coherent way which enables them to use technology to achieve their health objectives.

As well as requiring an infrastructure which can connect citizens, practitioners and authorities on-line, four key challenges remain for the full exploitation of health online:

- Electronic health services are growing across Europe and the world. Accordingly best practices must be identified and disseminated. In parallel European bench-marking criteria should be developed.
- Health related information is amongst the most frequently accessed information on the Internet. Yet at present the European citizen has very few resources with which to assess the quality and authenticity of this vital information.
- Public expenditure on health telematics tools and devices is a significant item in health budgets. Yet currently very little independent technology assessment exists to guide the purchaser's decision-making. Similarly, medical practitioners need access to up-to-date, networked public health data guidelines in order to assist their disease management decision-making.
- Europe currently holds a strong position in the nascent e-Health industry, which represents approximately 6% of the Information Technology market.
  Yet particular uncertainty persists in the health telematics related industry about responsibility and data protection, the legality of providing on-line medical opinions, as well as on-line pharmaceutical information and product supply.

Management and operation of the health services are a Member State competence, yet there is a role for the Community complementing their activities with the aim of improving public health, preventing human illness and diseases, and obviating sources of danger to human health (Article 152 Amsterdam Treaty).

Furthermore, in collaboration with key experts, a series of quality criteria has been established for health-related websites.

The Commission published a Communication on "Legal Aspects of e-Health in 2001". The objective was to review current legislation which has a bearing on the area, clarifying the existing legislation and building industrial confidence to enter the market. Data protection in the area of health care must be fully taken into account.

How do I validate my site for accessibility? 8.6.

Source:
http://www.macromedia.com/macromedia/accessibility/gettingstarted/validate.html

It is helpful to think of validating a site for accessibility as a process similar to editing an essay or another piece of writing. Leaving it until the very end is possible but will usually require a lot more work. Validation is something that should be done often as a site is developed. Frequent validation allows designers and developers to address accessibility problems before they become too severe.

Validation for accessibility should include a combination of automated and manual checks. Like a spell checker, the automated tools look for obvious problems with the accessibility of a page, while the manual tools generally look for continuity and flow of content. Macromedia Dreamweaver MX 2004 makes it easy to validate sites for accessibility. With reporting tools for accessibility and valid code, designers and developers may quickly identify problems on a single page, a collection of pages-even an entire site. Dreamweaver MX 2004 checks the selected pages for compliance with Section 508 standards or W3C Web Accessibility Initiative Guidelines, then generates a list of problems, so you can quickly find and repair the areas needing attention.

- Using Automated Checking Tools
- Validating Dynnamic Pages
- Performing Manual Validation

Using Automated Checking Tools

Perhaps the easiest way to begin the process of validation is to use one of the numerous free online validation tools. In most circumstances, these tools will provide a quick, if cursory, glance at the accessibility issues on a page. The oldest and best known of these tools is Bobby, from Watchfire Corporation.

Bobby (comment from Eurordis webmaster: Bobby may be tedious to use)
To use Bobby, enter the URL of the page to be checked in the form on the Bobby page (bobby.watchfire.com/bobby/html/en/index.jsp).

Bobby returns the page along with a report of obvious issues. Missing alternative text descriptions, missing frame titles, or absent Cascading Style Sheets (CSS) are easy to catch using a tool like Bobby. Bobby does not look at more complex and subjective problems such as tables used for data or the type of text used; Bobby was not intended to analyze these types of issues. Bobby's strength is in its simplicity and ease of use.

LIFT Online

LIFT Online is a powerful online tool available from UsableNet, a company specializing in web usability technology. LIFT Online evaluates five pages for free and then offers a fee-based service that provides a more comprehensive evaluation of subsequent pages or the whole site. LIFT is particularly helpful for getting an overall sense of the kinds of issues the designer/developer needs to address.

Comment from Eurordis webmaster: LIFT online is only free for the first year, then it is charged US$299/year.

LIFT can report when specific types of alternative text are required for objects such as spacer images. LIFT can detect a table used for data and evaluate the markup appropriately. LIFT can also evaluate a page using more general usability rules. These rules are not based on issues specifically faced by individuals with disabilities, but on usability issues common to all web users.

Accessibility Report for Macromedia Dreamweaver MX 2004

Application-based tools generally offer more comprehensive tools for validation. An excellent example is the Accessibility Report for Macromedia Dreamweaver MX 2004. Dreamweaver MX 2004 offers the ability to check individual pages or even an entire site against a customizable set of accessibility guidelines. The Accessibility Report in Dreamweaver MX 2004 offers a comprehensive set of tests for accessibility. Perhaps most important, it takes advantage of the authoring environment of Dreamweaver MX 2004 to point the web content designer/developer to specific places on the page in need of revision. It also provides further detail of the Section 508 standards and W3C Guidelines in the Reference panel.

HTML and CSS Validator

HTML Validator and CSS Validator from the W3C are particularly helpful for advanced users. These free tools do not check for accessibility issues; rather, they check for the proper use of HTML and CSS. This is particularly helpful for designers and developers who may understand coding in HTML and CSS but who are not familiar with relevant techniques for accessibility. The HTML and CSS validators can identify incorrect coding and point to a solution.

Validating Dynamic Pages

A common concern during the process of validation and repair is how to validate dynamic pages. Testing a dynamic page is similar to testing a static page. The primary difference is that the test covers the output of the page,

not the page itself. In most cases, making the necessary adjustments is comparable to making changes in HTML. While there are tools that do check dynamic code, many designers and developers report being equally comfortable using static checkers such as the Accessibility Report in Macromedia Dreamweaver MX 2004.

Dynamic design techniques for accessibility are more complex. These techniques, however, are more often intended to improve the process of accessible design rather than to affect directly the user's experience of a page.

Performing Manual Validation

Manual validation looks for a broad range of issues in the website or application. Manual validation should include at least three checks. In many cases, substantially more complex evaluations are necessary, but the three checks described here present some quick and simple ways to review the accessibility of a site.

First, evaluate the page using a screen reader or a text browser. Many screen reader manufacturers offer free demonstration versions of their software. Screen readers are complex, however, and not always easy to use. For those without visual impairments, IBM Home Page Reader is often easier to use than most screen readers. It offers a panel displaying the text that is read to the user. This visual display often makes it easier for novices to follow the contents of the page. Another advantage of Home Page Reader is that it is a speech browser rather than a true screen reader. Thus, designers and developers may include it in the list of preview browsers in Macromedia Dreamweaver MX 2004 and then turn it off when the evaluation is complete.

When checking a page in a screen reader, be sure to check for continuity in the content that is read to the user. Pay attention to text that includes cues reinforced by the screen reader. For example, an image used as a link should not include the word link in the text. The screen reader will inform the user that it is a link; therefore, referring to that fact in the text is redundant.

Second, carefully consider the sounds used on the site. If the sound is used to convey any content, check to make sure that the same information is available without sound. For longer audio tracks, be sure the audio is captioned.

Third, try using the page without touching the mouse. Use the Tab key to move among links and form objects on the page. Make sure the tab order follows a logical sequence. Also, be sure that users can reach every area on the site; pop-up menus and plug-ins can frequently create difficulties in this area.

8.7. How to reference sources

8.7.1 Journal Citations

In principle these are easy because in general, the same information is required whatever journal you are writing for. These are:

- Surnames of authors and full initials
- Title of journal
- (Title of paper)
- Volume number of journal
- (Issue number of journal)
- First (and last) page numbers of the article
- Year of publication

Some journals do not require the parenthesized items. However, just to make the would-be author's life more difficult, there is no standard way of quoting this information. Every possible permutation of the order of the information seems to be used by some journal or other.

(Journal of Bacteriology and other ASM journals):
Zinder, S.H., K.R. Sowers, and J.G. Ferry. 1985. *Methanosarcina thermophila* sp. nov., a thermophilic acetotrophic methane-producing bacterium. Int. J. Syst. Bacteriol. 35:522-523.

8.7.2 Book Citations

There is one unique identifier for a book that would make it very easy to trace, namely the International Standard Book Number (ISBN). Otherwise, you can mention authors/editors and publishers.
(Microbiology):
Baker, E.N. & Drenth, J. (1987). The thiol proteases: structure and mechanism. In Biological Macromolecules and Assemblies, vol. 3, *Active Sites of Enzymes*, pp. 312-368. Edited by J. McPherson. New York: Wiley.

Make sure that you get the chapter, page and volume numbers correct. If you cite the whole book, then it appears in the list under the editor's name. Book citations can only really be checked against the original book or a photocopy of the relevant chapters. In the US, the author/editor, publisher, ISBN and date of publication can be checked quickly and easily online via LOCIS, the Library of Congress Information Service (telnet locis.loc.gov).

ACKNOWLEDGMENTS

EURORDIS

Eurordis, the European Organisation for Rare Diseases, is a patient-driven network of rare disease organisations and individuals. Founded in 1997, Eurordis comprises 210 organisations in 16 European countries (as of May 2004).

Eurordis' mission is to build a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level, and - directly or indirectly - to fight against the impact of rare diseases on their lives.

Eurordis would like to thank all people and associations who participated in the development of this manual, in particular:

- participants in the European Workshops that were conducted throughout the project in Paris (January 2003), Namur (May 2003) and Paris (October 2003), from Belgium, Denmark, Estonia, France, Germany, Greece, Hungary, Italy, Portugal, Spain, Sweden, The Netherlands and the United Kingdom
- people who participated in the qualitative interviews on the information services in which they are involved
- participants in pilot training sessions in Hungary and Estonia
- people who shared materials from their own information services, or who translated their own documents
- and participants in the National Workshops of National Alliances (Belgium, Denmark, France, Germany, Italy, Spain, Sweden, The Netherlands and the United Kingdom)

The steering committee of this project included:

- Lesley Greene (Project Leader, Children Living with Inherited Metabolic Diseases (Climb), UK)
- Michele Lipucci di Paola (Associazone Veneta per la Lotta alla Talassemia, Italy)
- Elisabeth Kampmann-Hansen (Centre for Rare Diseases and Disabilities, Denmark)
- Anne Schaetzel (Maladies Rares Info Services, France)
- Yann Le Cam (Eurordis, Chief Executive Officer)
- Claire Marichal (Eurordis, Project Coordinator)
- François Houÿez (Eurordis, Project Manager)

Proofreading: Chris Owen-Roberts, Climb National Information and Advice Centre for Metabolic Diseases, UK.

Graphic design : Baptiste Ferrier - ferrier77@wanadoo.fr
Editing design : Harold Moreau - Vanessa Dambrine

Printed in March 2004 by Imprimerie Autographe, Paris

Published in March 2004

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:

Booklet 1 :
Preparing the group and delivering information

Booklet 2 :
Structuring, organising, and managing the group

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