INFORMATION SERVICES FOR RARE DISEASES
A manual to guide their creation and development

Booklet 2
Structuring, organising and managing the group
Booklet 1: Preparing the group and delivering information

Booklet 2: Structuring, organising and managing the group

3. STRUCTURING THE GROUP

3.1. Board of directors / trustees

3.1.1. What are the key duties of the board?

3.1.2. Board Member? Board of Directors? Board of Trustees? Or Board of Officers?

3.1.3. Short-term and long-term board strategies

3.1.4. Position title: Chairperson of the Board

3.1.5. Role of treasurer

3.1.6. How to evaluate the board of directors/trustees?

3.2. Executive committee

3.3. Basic ingredients of a board information system

3.4. Location

4. ORGANISATION. STAFF AND VOLUNTEERS. COMPOSITION

4.1. Composition (volunteers, staff)

4.2. Management and development of the group. Effective systems.

4.3. Volunteer and staff issues

4.3.1. Motivation and morale

4.3.2. Recruitment and selection process

4.3.3. Training and development

4.3.4. Volunteer / worker support and supervision

4.3.5. To develop and support volunteers / staff, you need a plan

5. EVALUATION OF THE INFORMATION SERVICE

5.1. Six Steps in the Evaluation Process

5.2. What parameters can you measure / evaluate?

6. ADDITIONAL PROJECTS

6.1. Outreach

6.1.1. Special outreach needs

6.1.2. People without a diagnosis

6.2. Related activities

6.2.1. Night Time Camps (Xeroderma Pigmentosum, UK)

6.2.2. Theatre group co-ordinated by a psychologist

6.2.3. Workshops with members / enquirers to assess needs of group / patients

6.2.4. Young people’s services (Climb), one-day training for health or educational professionals

6.2.5. Influencing research agenda and research funding

6.2.6. Policy making

6.3. Patient register

6.4. Parents’ organisation

6.5. Fundraising

6.6. To create a sense of community

6.7. Plan to develop and support staff

6.8. Telephone helplines association
3. STRUCTURING THE GROUP

Even though this section may look too detailed for a small organisation, it is always important to have an idea of how to best structure the service prior to starting activities, even if at a restricted level. Refer to your own country’s legal system for the organisational structure of the group. Legal requirements vary from country to country.

3.1. Board of directors / trustees

The board constitutes a fundamental pillar of the group. Why do you need one? If your service structure is strong, you will find that the board can bring well-worked out and well-researched proposals to the full group. The people who care the most about the issue can propose solutions so that usually even a very large group can come to consensus quite easily. If not, you may have to postpone a response until the entire group has a chance to think it over, get more information for themselves, propose an alternative or do whatever they have to, to participate in a decision which will be best for the group as a whole.

You can have an executive committee made up of the officers and perhaps a member or a few at large, who are authorised to act when required between regularly scheduled service meetings. You can also give input to a committee (or an individual), and then authorise them - and trust them - to make a final decision on a matter.

3.1.1. What are the key duties of the board?

There are many duties for which the board can take responsibility. By delegating responsibilities and duties to them, other members can dedicate more time to information delivery. The following duties are typical tasks for a board:

- Determine mission and purposes
- Select the executive staff through an appropriate process
- Provide ongoing support and guidance for the chief executive officer; review his/her performance (if appropriate)
- Ensure adequate resources and manage them effectively
- Determine and monitor programmes and services
- Enhance public image
- Serve as a court of appeal
- Assess its own performance

Members of Boards of Directors -- most frequently the Board President -- occasionally lose sight of the generally accepted operating principle that no action or directive of functional committees of the Board, or of individual Board members, can have any force or effect unless it is approved by the full Board. Thus, Board committees and individual members may make recommendations for consideration and action by the Board, but they would normally be considered “out of order” if they attempted to give direct instructions or orders to the Executive Director and/or members of his/her executive staff. Those orders should generally come in the form of resolutions adopted by the full Board.

3.1.2. Board Member? Board of Director? Board of Trustees? Or Board of Officers?

TRUSTEE

A trustee is:

- A member of a governing board elected or appointed to direct the policies of an institution.
- A person, often one of a group, who controls property and/or money for the benefit of another person or an organisation.

BOARD OF DIRECTORS

A group of people chosen to govern the affairs of a corporation or other large institution. There is no real difference between a Board of Trustees and a Board of Directors. In practice, the difference mainly applies to the UK and Ireland. National laws usually define roles and positions for non-profit organisations.

BOARD OF OFFICERS

At a minimum, three positions are often legally required within a board: president (or Chairperson)

- Assist the Chief Executive Officer in recruiting volunteers and management if appropriate.
- Chair meetings of the Board. See that it functions effectively, interacts with management optimally, and fulfils all of its duties. With the Chief Executive Officer develop agendas.
- With the Chief Executive Officer recommend the composition of the Board Committees. Recommend committee chairpersons with an eye to future succession.
- Assist the Chief Executive Officer in recruiting Board members and other talent for whatever volunteer assignments are needed.
- Reflect any concerns management has with regard to the role of the Board of Trustees or individual trustees. Report to the Chief Executive Officer the concerns of the Board of Trustees and other constituencies.
- Present to the Board an evaluation of the service’s mission and purpose.
- Prepare a review of the Chief Executive Officer and recommend his/her salary for consideration by the appropriate committee.
- Annually focus the Board’s attention on matters of institutional governance that relate to its own structure, role, and responsibilities.
- Act as an additional set of eyes and ears.
- Serve as an alternative spokesperson.
- Fulfil such other assignments as the Chairman and Chief Executive Officer agree are appropriate and desirable for the Chairman to perform.

See an example of a position title for a member of the board of directors in the toolbox 7.5 page 8.

Short-term and long term strategies 3.1.3.

Usually, boards work from month to month and somehow lose sight of what is going to happen in five or ten years. This can happen easily, and boards slip into this habit. However, boards should set aside some time at each meeting to start thinking long-term and long term thinking should be shared at regular intervals with the whole organisation; volunteers, staff and sometimes enquirers should be invited as well. This could be organised within a seminar or a retreat. Collect all ideas throughout the year and use them to evaluate and modify your organisation’s long-term plan.

Position title: Chairperson of the board 3.1.4.

The Chairperson of the Board ensures that the Board fulfils its responsibilities for the governance of the service. He/she acts as a partner to the Chief Executive Officer, helping him/her to achieve the mission of the service (if appropriate). He/she optimises the relationship between the board, volunteers and management if appropriate.

RESPONSIBILITIES

- Chair meetings of the Board. See that it functions effectively, interacts with management optimally, and fulfils all of its duties. With the Chief Executive Officer develop agendas.
- With the Chief Executive Officer recommend the composition of the Board Committees. Recommend committee chairpersons with an eye to future succession.
- Assist the Chief Executive Officer in recruiting Board members and other talent for whatever volunteer assignments are needed.
- Reflect any concerns management has with regard to the role of the Board of Trustees or individual trustees. Report to the Chief Executive Officer the concerns of the Board of Trustees and other constituencies.
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See an example of a position title for a member of the board of directors in the toolbox 7.5 page 8.
3.2. Executive committee

When a board of directors is large, or meets infrequently, or is widely scattered geographically, it may decide to create a smaller group, often called the Executive Committee, that can act for the board as a whole between meetings.

The membership, powers and reporting responsibilities of the Executive Committee need to be spelled out carefully in the board’s own rules (often called the By-Laws). Boards may also, from time to time, hand over specific problems or questions to such a committee for research, decision or action. Doing so must be permitted by the By-Laws; the By-Laws may set limits on what can be delegated in this way. State corporations’ statutes often place limits on the kinds of actions that can be delegated by a board of directors to an executive committee (or to any other group).

It is important to remember that the board of directors holds both the authority and the responsibility for every action the organisation takes. The board can, in certain circumstances, delegate its authority. Commonly, of course, boards delegate responsibility for routine operations to staff as well as asking committees and other groups of volunteers to tackle specified tasks on its behalf.

Having a variety of ways of making decisions can be a source of tension or conflict. No matter what the strict legal requirements may be, such tension or conflict can be damaging to a service, especially if it continues without resolution over a long period. It is worth investing creativity and good will - even money to hire facilitators or consultants -- to identify the sources of recurrent conflict and to develop new procedures or rules to reduce tensions in the future.


3.3. Basic ingredients of a board information system

Every board must decide for itself exactly what information it needs. For most groups, however, the following checklist is a starting point.

- **AFTER EACH BOARD MEETING**
  - Minutes
  - Notice of next meeting

- **MONTHLY**
  - Financial report
  - Significant published articles about the service

- **QUARTERLY**
  - Financial report

- **REGULARLY, WHEN APPROPRIATE**
  - Memo from chief executive summarising current activities, accomplishments, and needs
  - Updated material for the board handbook
  - Advance copies of publications, brochures, or promotional materials
  - Annual report

Home as Headquarters has good and bad points: low cost, available, familiar, but intrusive in private life, difficulties arise when the home owner envisages ceasing his/her position in the group.

Wheelchair access to head offices is crucial. Distance from the capital involves travel to lobby. Recruitment efforts may be easier in the capital city. An umbrella organisation can help and offer to host the group.

A confidentiality area should be dedicated to responding to incoming calls or to discussions with enquirers.

Looking for a well-suited solution for its headquarters, ADAC in Spain benefits from a 5-year renewable lease with a low rent, in a governmental building shared with other non-governmental organisations.

Another possibility is to share a location with another patient group or within a larger non-governmental organisation.

3.4. Location

Looking for a well-suited solution for its headquarters, ADAC in Spain benefits from a 5-year renewable lease with a low rent, in a governmental building shared with other non-governmental organisations.
4. ORGANISATION STAFF AND VOLUNTEERS COMPOSITION

4.1. Composition (volunteers, staff)

Volunteers and employees are essential elements of a non-profit organisation’s ability to achieve its mission. Volunteers are unique to non-profit organisations, and are a vital resource in governance, administrative, and service capacities. Non-profit organisations’ human resource policies must be fair, establish clear expectations, and provide for meaningful and effective performance evaluation for both paid employees and volunteers.

**Volunteers/employees**

• Employees and volunteers should be committed to the mission of the organisation and competently, efficiently, and professionally perform the duties they agreed to assume.
• The employees and volunteers of the organisation should broadly reflect the diversity of their organisation’s constituencies.
• The organisation should invest in the training of employees and volunteers as a mean to ensure quality management and service.
• The organisation should have a system in place for written evaluation of employees and volunteers by their respective supervisors, at least annually.
• The organisation should have a system in place for the succession of employees, most notably for the executive director.
• New employees and volunteers of the organisation should receive clear orientation to the mission of the group and its policies and procedures, job definitions and expectations, and a defined workspace.

**Effective meetings**

When holding meetings, whether with the whole group or in working groups, some tips can help to make meetings effective:

• Where an important decision has to be made before the next planned meeting explore other methods of communicating such as organising a conference call between the relevant committee members
• Make sure that the minutes taken are an accurate record of the meeting before circulating

**The role of the chairperson**

The chairperson has an important role in ensuring the smooth running and effectiveness of the meeting. It is essential that meetings are managed efficiently and that there is good communication and relationships with all members of the committee.

The experience of each committee member will be different and this can be a source of strength or weakness.

If a decision cannot be reached about a specific issue agree a time limit for it to be discussed at a later date

**4.2. Management and development of the group. Effective systems**

Once you have created your structure, you need to verify that the rules and protocols apply in daily life: you need to determine whether your model is effective. There are important activities that particularly need to be run in an adequate manner: meetings, dealing with difficult issues.

**Effective meetings**

When holding meetings, whether with the whole group or in working groups, some tips can help to make meetings effective:

• Try to keep to the point when discussing items and allow everyone to contribute. Each member’s point of view should be respected.
• Ensure that individual responsibility for any task agreed at the meeting is understood and accepted.
• Where possible use sub-committees to deal with specific tasks such as organising a family day.
• If a decision cannot be reached about a specific issue agree a time limit for it to be discussed at a later date.

**When chairing meetings - do not forget:**

• Be careful about timing – allow plenty of time for discussion but have a definite end time for the meeting and do not overrun.
• Invite everyone involved to put forward their point of view and do not allow one person to dominate the meeting.
• Allow open debate – everyone should be allowed to contribute to the discussion without fear of being unfairly challenged.
• When discussing important items ensure that everyone has all the relevant information.
• Try to keep the debate balanced – if you wish to participate as an advocate for one point of view on a major item hand the chair to someone else.
• Make sure that each item is concluded before moving on: summarise the decision and ensure that action points are recorded in the minutes.
• At the end of the meeting agree the date and venue of the next meeting.

**Dealing with difficult issues**

As the membership grows the group may find that it has to deal with difficult issues. These might be inappropriate contacts, families with difficult personal circumstances and conflict within the committee. In most cases the problem can be easily dealt with but occasionally the group may find itself in a situation that is more difficult to resolve. The following guidelines may help:

• Tackle problems as soon as they arise rather than leaving them to solve themselves.
• Where possible use committee meetings to discuss difficult issues.
• Avoid responding to a difficult issue in the heat of the moment – if it cannot be dealt with properly in committee work out how best to deal with it e.g. writing rather than telephoning.
• Establish ways of communicating regularly with other members of the committee between meetings, for example by organising conference calls.
• Avoid dealing with difficulties on an individual basis – it can help to get other points of view.
• Do not feel pressurised into making individual decisions that may affect the group without prior discussion with other members of the committee.
• Avoid becoming individually involved in personal criticism – response to this should come collectively from the committee.
• Seek advice from other sources or organisations where necessary.

Volunteer and staff issues 4.3.

At some point, the development of your group activity may require you to hire paid staff. This is often a dilemma, as a frequent fear is of movement away from grass roots when becoming more “staffed”.

When recruiting staff, be aware of high turnover in the advocacy area (frequent travel, and low salaries). Extensive team travelling may be adequate for singles, but less acceptable for family life. As far as possible, do not make staff travel too much.

**Good Practice:**

The Danish Rare Disease Centre is a good reference point with 12 years experience and 10 employees.

**Motivation and morale 4.3.1.**

Keep staff and volunteers at the same level: it is harder to develop the same level of experience and know-how with volunteers. The risk of feeling too self-confident exists both for staff and volunteers.

**Recruitment and selection process 4.3.2.**

Costs of staff in a capital city (but not only) are a major obstacle. You should prefer a working contract rather than an ad hoc honourarium, as sponsors and funders almost always prefer organisations to employ staff. Recruitment difficulties in social services are real, even efficient administrative staff are not always easy to find in the job market.

In some situations, for example when two different organisations are merging, you can inherit less skilled or outdated staff.
Evaluation of the information service

An evaluation system is the means by which an organisation determines the impact of its programmes on the areas on which it focuses. To evaluate the adequacy of an information service with the enquirers’ expectations or its functionality is equally important.

It is important for evaluation purposes that goals and objectives are measurable. If your programme is doing things that cannot be evaluated or measured, you may be unable to demonstrate that you are achieving anything.

Choose the criteria by which you will judge whether your goals and objectives have been achieved. Common ways to measure outcomes include the following:

- Counting the number of enquirers served (this works fairly well for public meetings, workshops, telephone lines, e-mails, one-to-one interviews).
- Using appropriate tests or questionnaires at the point of intake (the point at which an enquirer enters your service process) and at repeated times.
- Comparing reported behaviour before and after programme involvement (through enquirers who contact several times, through the increase of contacts after an advertisement campaign, or the increase of subscriptions to your newsletter; through an increased diversity of enquirers, invitations from specialised centres or hospitals to train medical staff...).
- Surveying enquirers (and their families and carers) to determine satisfaction with the service.

Evaluation can also apply to each volunteer or staff member activity. This is not a procedure to control what people are doing, but a self-evaluation system for each person to assess the strengths and weaknesses of what they do, and to propose changes.

For more information on this subject, MPS in Great Britain conducted an Assessment Study “a 6 months study on why patients are coming to us”. This study is to be renewed, and you can contact MPS to learn more on the methods used and lessons learned from this study. Contact the Society for Mucopolysaccharide Diseases (MPS): 46 Woodside Road, Amersham Buckinghamshire HP6 6AJ, England. Tel.: + 44 1494 4341 56. E-mail: mps@mpssociety.org.uk or visit the website: http://www.mpssociety.co.uk/about.htm.

Maladies Rares Info Services in France is developing a questionnaire for enquirers. Contact: Maladies Rares Info Services Plateforme Maladies Rares - 102 Rue Didot F-75014 Paris, France. Tel.: + 33 1 56 53 81 27. E-mail: info-services@maladiesrares.org.

Six steps in the evaluation process

1. Decide on the purpose of the evaluation
   - What is the purpose of the evaluation?
   - What do we want to know? Why? How will we use the results of the evaluation?

2. Set up an evaluation structure
   Options include: Committee, outside evaluator, self-evaluation, a combination of these etc.

3. Prepare the evaluation design
   - What will be the focus of the evaluation?
   - What constitutes success (and degree of success) in the programme or service that is being evaluated?
   - What external factors may affect the success of the programme or service?
   - What information is needed to carry out the evaluation?

4. Gather information
   - Common techniques for information-gathering include: interviews, questionnaires, reviewing documents/databases, public surveys, media scans, focus groups etc.
   - Sources of information frequently include: clients, staff, volunteers, board and the community.

5. Analyse information
   - It is often helpful to review and analyse information during the evaluation process, and not simply at the end - this can correct gaps or problems, as well as begin to identify trends.

6. What are the appropriate tools to gather the information needed?
and possible conclusions.

- No final conclusions should be drawn until all the information is gathered and analysed.
- After the evaluation, decisions should be made about action steps in the light of the evaluation.
- Action and implementation

5.2. What parameters can you measure / evaluate?4

Assessing the impact of your information service follows the same basic ground rules as project evaluation. You need to be clear about your objectives, explicit about the activities that will realise the objectives, logical about the way in which you gather data and evaluate it, and pragmatic about how much time you spend on the whole exercise. If you’re spending more than one tenth of your overall budget on evaluation, then you’re probably looking for evidence that doesn’t exist.

**IMPACT**

Concrete changes in the lives of the ultimate beneficiaries, i.e. rare disease patients.

**OUTCOMES**

These are the changes brought about as a result of your activities. For example, a survey on orphan drug prices in Europe reflects significant differences within Member States and led the commission to investigate on such differences.

**OUTPUTS**

These are the direct results of your activities over which you have most control (i.e. producing printed materials, number of calls responded to, hosting a workshop to share research findings which lead to outcomes, etc.)

Most evaluation reports focus on outputs rather than outcomes and impact. This is because outputs are more visible and happen almost immediately after the intervention (a time when project staff can witness and report on completed activities).

**INPUTS**

These are the resources – both people time and actual costs – that are incurred in undertaking the activities (e.g. 40 days of a researcher’s time to do a literature search; 24 days of a social worker’s time to design and conduct field surveys; air fares, subsistence, costs of hiring a conference venue for a seminar to share findings).

The ultimate purpose of the evaluation is to have an impact on the work of the service. This will include the areas originally identified in the purpose of the evaluation, but there may also be other constructive uses of the information.

**INDICATORS**

Things to look for include the process itself, as well as evidence of the actual impact of the intervention. Questions you should be asking about the process of the project include:

- Are the techniques being used working well? For example, is the media campaign generating media coverage of the right sort, in the right places?
- Are the policymakers that you seek to engage responding positively?
- Are other organisations ‘coming on board’ and beginning to join forces with you?
- Are the people being reached those that you want to target?
- Is there evidence that your targets (i.e. those in a position to bring about change) are being reached and are responding?
- Are they taking action? Is the action likely to bring you closer to realising your objectives?
- Are you involving, or collaborating with the right people, organisations or bodies?
- In retrospect, were the techniques used in the way they were intended to work?

In the annexes, you can find an example of an evaluation form adapted to a meeting or a workshop.

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**ADDITIONAL PROJECTS 6.**

**Outreach 6.1.**

**Special outreach needs**

**People without a diagnosis**

- Possible links can help people without a diagnosis:
  - La Chaînette (www.lachainette.org in French, or www.networkchain.org in English)
  - Orphanet: list of medical centres for expert advice or second medical opinion
  - Istituto Superiore di Sanità in Italy

**Related activities 6.2.**

**Nigth Time Camps (Xeroderma Pigmentosum, UK)**

**Theatre group co-ordinated by a psychologist**

**Workshops with members / enquirers to assess the needs of the group / patients**

**Young people’s services (Climb), one-day training**

**Influencing research agenda and research funding**

Activities can also consist in initiating and supporting research for rare diseases. To promote research, information services can propose four kinds of services (not exhaustive):

**To point out research needs**

Patients’ organisations are efficient voices to guide research priorities: they can be consulted by public or private research institutions, they can participate in funding allocations, they can evaluate research projects, etc. Websites or written documents can underline what is needed and explain why.
FUNDRAISING FOR RESEARCH
Funds that originate from patients’ organisations are precious for research: they are often more flexible and a useful complement to grants that are obtained from governments or notable research foundations. To fund research is also an excellent approach to start a debate with scientists and researchers and to exchange information.

TO CREATE AUTONOMOUS RESEARCH CENTRES
Few patients’ organisations have resources to create their own research centre. But it is a possibility, like Association Française contre les Myopathies (APF) in France that sponsors research laboratories. It is the ultimate stage of involvement in research and a lot of information on diseases can be generated.

TO COLLECT DATA FROM PATIENTS AND MEMBERS
Patients can report specific issues that can serve to design research concepts and proposals: a study to evaluate the role of a symptomatic treatment against specific side effects, suggestions to improve a medical device or prostheses, explanations of the pathophysiology of a disease, etc. A questionnaire to collect such reports and ideas could be proposed by the information service. The analysis of feedback can be performed with the collaboration of scientists and doctors.

6.2.6. Policy making
There are many domains where patients groups can make their voice heard and improve care for rare diseases. For example, other rare disease groups may help.

GETTING THE SUPPORT OF OPINION LEADERS AND POLICY MAKERS
Many of the basic strategies for approaching and persuading opinion leaders are the same whether they are at the community, regional, or national level.

Target efforts
Assess which opinion leaders’ agreement and support will be necessary for the advocacy campaign to reach its goals. Decide whom to approach and in what order.

Be thankful
Always begin by thanking the opinion leader for his or her time. Opinion leaders who support rare disease networks may be taking a controversial and difficult position. Sincere thanks will be greatly appreciated.

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The Guidelines for Good Practice is a completely updated and revised 3rd edition, focusing on issues:

- Confidentiality
- Training
- Evaluation
- Helplines and the law

This edition has entirely new chapters on:

- Setting up a helpline
- Working alone
- Emergency helplines

A comprehensive reference to use in training, keep by every helpline phone and consult if setting up a helpline.

6.3. Patient register

To bring together isolated patients. Check legacy (Commission Nationale Informatique et Libertés, CNIL) of such lists.

6.4. Parents’ organisation

Perce Neige Belgium
Events like dinners, for mutual help, exchange of medical services.

6.5. Fundraising

In Germany, the public prosecutor or a judge can request convicts to pay a penalty to a charitable organisation (this is not tax deductible) even if the charitable organisation is not a party in the legal case.

6.6. To create a sense of community

Alliance Maladies Rares holds different meetings:

4 RIME
Réunion d’Information des Membres, members meetings/year:
- Law
- Every day life
- Research
- How to run an organisation
- Events and actions in the Alliance
About 40 to 50 participants

3 Forums
3 forums/year on particular themes:
- Orphan drugs
- Diagnosis
- Research
- Social rights
All patients’ organisations dealing with rare diseases in France are invited, with other stakeholders, about 100 to 130 participants.

6.7. Plan to develop and support staff

Contact a Family GBR
EURORDIS

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

Europdis’ 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.

Europdis 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 (Associazione 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)
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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

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