EURORDIS
European Organisation for Rare Diseases

INFORMATION SERVICES FOR RARE DISEASES

A manual to guide their creation and development

Booklet 2

Structuring, organising and managing the group

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European Commission

Table of contents

Booklet 1: Preparing the group and delivering information

Booklet 2: Structuring, organising and managing the group 4

3. STRUCTURING THE GROUP 4
3.1. Board of directors / trustees 4
3.1.1. What are the key duties of the board? 4
3.1.2. Board Member? Board of Directors? Board of Trustees? Or Board of Officers? 4
3.1.3. Short-term and long-term board strategies 5
3.1.4. Position title: Chairperson of the Board 5
3.1.5. Role of treasurer 6
3.1.6. How to evaluate the board of directors/trustees? 6
3.2. Executive committee 6
3.3. Basic ingredients of a board information system 7
3.4. Location 7

4. ORGANISATION. STAFF AND VOLUNTEERS. COMPOSITION 8
4.1. Composition (volunteers, staff) 8
4.2. Management and development of the group. Effective systems. 8
4.3. Volunteer and staff issues 9
4.3.1. Motivation and morale 9
4.3.2. Recruitment and selection process 9
4.3.3. Training and development 10
4.3.4. Volunteer / worker support and supervision 10
4.3.5. To develop and support volunteers / staff, you need a plan 10

5. EVALUATION OF THE INFORMATION SERVICE 11
5.1 Six Steps in the Evaluation Process 11
5.2 What parameters can you measure / evaluate? 12

6. ADDITIONAL PROJECTS 13
6.1. Outreach 13
6.1.1. Special outreach needs 13
6.1.2. People without a diagnosis 13
6.2. Related activities 13
6.2.1. Night Time Camps (Xeroderma Pigmentosum, UK) 13
6.2.2. Theatre group co-ordinated by a psychologist 13
6.2.3. Workshops with members / enquirers to assess needs of group/patients 13
6.2.4. Young people's services (Climb), one-day training for health or educational professionals 13
6.2.5. Influencing research agenda and research funding 13
6.2.6. Policy making 13
6.3. Patient register 16
6.4. Parents' organisation 16
6.5. Fundraising 16
6.6. To create a sense of community 16
6.7. Plan to develop and support staff 16
6.8. Telephone helplines association 17

Booklet 3: Toolbox and annexes

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 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 prepare proposals 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?[1]

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 effective organisational planning
- 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:[2]

- 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 of the board), treasurer, and general secretary. These positions can be elected among board members by board members following their election, or by the members of the organisation at the general assembly. The Board of officers may be able to meet more easely and more frequently. They can expand the group by co-opting or any other process, for example if staff member (accountant, Chief Executive Officer...) needs to participate in decisions.

3.1.3. Short-term and long term strategies

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 many 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-tern plan.

3.1.4. Position title: Chairperson of the board

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.
- Present to the Board an evaluation of the pace, direction, and operational strength of the organisation.
- 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 relationship to management. Be assured that the Board is satisfied it has fulfilled all of its 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.

Booklet 3
Toolbox

[1] The Internet Nonprofits Centre

[2] hyperdictionary.com

3.1.5. Role of a treasurer

Booklet 3 Toolbox

The treasurer shall:
- Keep accurate financial records for the organisation
- Deposit money, drafts, and cheques in the name of and to the credit of the organisation in the banks and depositories designated by the board
- Endorse for deposit notes, cheques, and drafts received by the organisation as ordered by the board, making proper vouchers for the deposit
- Disburse funds and issue cheques and drafts in the name of the organisation as ordered by the board
- Upon request, provide the president and the board an account of transactions by the treasurer and of the financial condition of the organisation
- Perform other duties prescribed by the board or by the president

See Toolbox 7.6, page 9.

3.1.6. How to evaluate the board of director / trustees

An annual board assessment gives each board member the opportunity to evaluate the board's overall effectiveness at accomplishing its goals in a variety of activity areas. It can be scheduled to occur during a board meeting, or completed by board members in their own time and returned to the service. Results of the evaluation can be shared at the next board meeting, and appropriate follow-up then determined. A ranking system reflecting the level of accomplishment within each task may be useful (1=effective performance, 2=adequate performance, 3=inadequate performance, U=uncertain), and activities can be grouped into the following categories:
- Knowledge of board financial, legal and public responsibilities
- Representation to the public by the board
- Understanding and communication of the service's mission
- Service's compliance with legal regulations, licensing and other standards
- Effectiveness of board practice: Bylaws, committees, procedures
- Approval of outside counsel (legal, accounting, managerial)
- Relationship with the Executive Director
- Hiring, evaluating, managing, and compensating the Executive Director
- Strategic planning
- Policy development and approval
- Oversight of the service's financial structure and activity, including income, expenses, borrowing, insurance coverage, audits, bank relations, fund-raising, and other financial procedures
- Board performance: meeting attendance, discussion, and participation
- Board succession and nomination process
- New board member orientation

3.2. Executive committee

Booklet 3 Toolbox

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.

See Toolbox 7.7, page 9, and 7.14, page 17.

Basic ingredients of a board information system 3.3.

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

AT LEAST TWO WEEKS BEFORE EACH BOARD MEETING
- Agenda
- Information about issues for discussion, when appropriate
- Financial information
- Committee reports

AT LEAST TWO WEEKS BEFORE THE BOARD MEETING AT WHICH IT IS DISCUSSED
- Annual budget
- Audit report
- Strategic plan

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

Location 3.4.

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.

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.

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
- 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 but may also, on occasions, create difficulties. Try to resolve any conflict within the committee as quickly as possible to minimise the risk of a damaging effect on the running of the group.

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 honorarium, 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.

Some groups can hire students who benefit from scholarships: ADAC in Spain hires a philology student (part-time) in charge of translation, and a history student in charge of archiving. Accountability and administration are carried out "pro bono" by a private company (on a partly voluntary basis).

4.3.3. Training and development

Training new staff can require 2 years.

4.3.4. Volunteer / worker support and supervision

Have a good team to delegate work.
Avoid burnout.

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

EVALUATION OF THE INFORMATION SERVICE 5.

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[3] 5.1.

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?

SET UP AN EVALUATION STRUCTURE

Options include: Committee, outside evaluator, self-evaluation, a combination of these etc.

PREPARE THE EVALUATION DESIGN

- What will be the focus of the evaluation?
- What constitutes success (and degrees 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?
- What are the appropriate tools to gather the information needed?

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.

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

[3] These materials have been adapted with permission from United Way of Canada Centraide Canada's **www.boarddevelopment.org** Website. All rights reserved.

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

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.

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).

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 targets and channels of communications used to reach them, the most appropriate?

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

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[4] Advocacy Impact Assessment Guidelines. Megan Lloyd Laney Communications and Information Management Resource Centre (CIMRC), CAB International, Nosworthy Way, Wallingford, OXON OX10 8DE, UK. E-mail: **cimrc@cabi.org.** Accepted: 24 March 2003

ADDITIONAL PROJECTS 6.

Outreach 6.1.

Special outreach needs 6.1.1.

TEACHERS, SCHOOL EDUCATORS
Importance of good information: to reduce fear when preparing children to welcome another child with a rare disease at school, to prepare everything needed on site, to contribute decreasing stigma on diseases. The Prader-Willi Federation in Italy prepares teachers to take care of affected children at school.
- You can use computer generated flyers which give the name of the group, the service provided and how to contact you, or the location and the dates/times of the next meetings. You can place these in doctor's offices, treatment clinics, and hospitals. Later, members can create a two-colour brochure or leaflet and place these in the same places, including the offices of welfare services.
- You can consider having your service announced in the local newspapers. Flyers and brochures can urge people to call your group contact if interested in attending a meeting.
- You can develop a web page on the Internet.

People without a diagnosis 6.1.2.

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
- OMIM (Online Mendelian Inheritance in Man)
- Erfocentrum in The Netherlands: people without a diagnosis can get tips on how to find more information in the library or on the Internet. A brochure is developed especially for this group of people.

See Toolbox 7.13, page 15.

Booklet 3
Toolbox

Related activities 6.2.

Nigth Time Camps (Xeroderma Pigmentosum, UK) 6.2.1.

Theatre group co-ordinated by a psychologist 6.2.2.

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

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

Influencing research agenda and research funding 6.2.5.

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 notorious 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 (AFM) 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 have successfully conducted policy campaigns:

- With the goal to improve political awareness
    - Rare disease groups participate in a study group at the National Assembly (France)
    - Elaboration of proposals on specific laws (anti-discrimination law for disabled in Germany)
- With the goal to promote adoption of legislation to create national network of healthcare institutions for rare diseases and a national register of rare diseases and national centres backed by the minister of health

Health authorities often create advisory bodies, they are time consuming and you may not have enough volunteers to participate in all study groups; a reason why creating a National Alliance may help.

It is crucial to provide a non-confrontational tool for advocating care needs.

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.

Be professional

Avoid criticising other leaders, public figures, or organisations.

Be focused

Patients' representatives frequently feel they have to share as much information as possible with a leader, but too much information will only confuse the message and dilute the point, especially if the opinion leader's time is limited.

Be prepared

As a part of the preparation, try to determine the opinion leader's position on the issue. The position can be discerned through comments he or she has made, the kind of events the leader attends, his/her political affiliation, and past policy decisions. Working within a network helps with this research, because at least one organisation will be likely to have had some contact with the opinion leader. Explore the opinion leader's personal connections with rare disease: is he or she a parent, uncle, aunt, or grandparent of a patient?

Make a personal connection

Let the opinion leader know about friends, relatives and colleagues in common. A personal connection may make the difference in the effectiveness of the visit. Leaders are often more likely to remember and think favourably about a visit that had some personal connection to them.

Be an information source

Some opinion leaders have so much to think about that they cannot focus too long on any one issue. They may not be as informed as they would like to be.

Tell the truth

There is no faster way to lose credibility than to give false or misleading information to an opinion leader.

Know who else supports the issue

Opinion leaders like to know which other leaders and organisations support the position. Providing this information illustrates support and may provide the opinion leader with additional reasons to support the position.

Know who disagrees with the issue

The opinion leader may be faced with a difficult decision if another powerful institution or individual opposes the issue. Anticipate who the opposition will be and what their positions are. Discuss with the opinion leader the potential arguments of the opposition, and why the leader should not support that position. When there is opposition, the ability to anticipate criticism and defend the issue will make a difference.

Acknowledge when more information is needed

If an opinion leader wants information that is not available, or asks something not known, admit a lack of knowledge. Then, offer to get the information he or she is looking for and do so as quickly as possible after the meeting.

Make a specific request

Walk in knowing exactly what the opinion leader will be asked to do in support of the issue. For example, that the leader put his or her name on a letter, change a school policy, answer a question, make a public endorsement, or support increased funding for research programmes.

Follow up

Find out if the opinion leader did what he or she committed to doing. Send a letter of thanks after the conversation, and restate the position. Thank the leader for any supportive actions. Politely ask for an explanation if he or she has failed to follow up on promises.

Do not create enemies

It is easy to get emotional over strongly felt issues. Be sure to leave the relationship with the opinion leader on good terms to permit working with him or her again.

Communicating with Opinion Leaders By letter

Identify the writer, organisation, issue, and relationship with the opinion leader

If possible, use paper with a letterhead. When writing on behalf of an advocacy network, identify member organisations either in the letterhead or in the text of the letter. Provide a one-line mission statement or statement of purpose that gives the leader a sense of what is at stake. If writing on behalf of a network, include complete contact information for one or two people to whom the opinion leader can respond.

Mention a specific issue

The letter will be more effective if it concentrates on one specific issue.

Be brief and succinct

A one-page letter has the most impact. Give the main point in the first paragraph and cover only one issue per letter. For background, include a fact sheet, newspaper clipping, or short publication that discusses the issue in greater depth. Respectfully, but clearly, indicate what kind of action is desired from the opinion leader.

Make it personal

Opinion leaders are more likely to pay attention and remember letters that include real life experiences. Explain why the issue is important and how the leader's decision will affect people. Describe an experience that illustrates the point. Personal communication can be just as effective as organised campaigns.

Ensure that the opinion leader receives the letter

Verify that the address is correct. If the opinion leader is local, hand deliver the letter.

Follow up

If the opinion leader has a phone, make a quick call to confirm that he or she received the letter. If the opinion leader does what was asked, write again to thank him or her.

FACE-TO-FACE VISITS

Schedule a meeting

Call the opinion leader, or send a representative to schedule a meeting. Make appointments well in advance, prepare for the meeting, confirm the meeting, and invite other colleagues. Keep a record of who attended, what information was shared, and any actions promised.

Be flexible

Expect interruptions and changes in schedule. Be willing to accommodate the opinion leader's busy schedule. If the opinion leader has to reschedule, set up another meeting right away.

Be prompt

Do not be late, as it sets a bad tone for the meeting before it has even started.

Be prepared

Make the most of the visit. Plan the presentation in advance and divide up roles for group members to take on, including a note taker. Plan a 5-minute presentation (10 minutes at the most) and stick to the point. Introduce members of the group, but have one member do most of the talking. Make important points in a clear and succinct manner, and let the opinion leader know respectfully, but clearly, what he or she is being requested to do.

Leave something behind
Develop an information packet to leave with the opinion leader. It should include a short (one or two pages) summary about the group, the issue, the action requested, background information, and any other materials or fact sheets that may be useful to the leader. Avoid loading the packet with too much information. Leave out long publications, detailed reports or research, and unrelated materials, unless the opinion leader expresses an interest in seeing this information as well.

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

Telephone helplines association 6.8.

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.

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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.

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- participants in pilot training sessions in Hungary and Estonia
- people who shared materials from their own information services, or who translated their own documents
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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

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