



The Value+ Toolkit

For Patient Organisations On Meaningful Patient Involvement
Patients Adding Value To Policy, Projects And Services



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Dear Reader,

This toolkit for patients and patient organisations has been prepared as a result of the Value+ project, which addressed the growing need realised by the European Patients' Forum (EPF) and the European Commission (EC) to support the exchange of information and experience on good practice relating to patient involvement in EC projects.

EPF is a not-for-profit, independent organisation and umbrella representative body for patient organisations throughout Europe. Representing the EU patient community we advocate for patient-centred equitable healthcare, and the accessibility and quality of that healthcare in Europe.

We strive to put patients and patient organisations at the centre of policy-making initiatives related to health. Your specific knowledge and experience is crucial to play an active role in decision-making that affects all our patient constituencies. This is at the heart of what EPF considers to be meaningful patient involvement.

There may have been times when you wanted to apply for funding or become a partner in a proposal, but did not know what steps were needed to even begin the process. This toolkit is designed to support you with the skill set needed to bring you to the forefront of EC co-funded projects. It will also help you plan, evaluate and manage the project process and provide the necessary information to promote good practices in patient involvement.

This toolkit would not have been possible without the dedication of members from each Value+ project partner organisation. We want to thank you for your invaluable insight and input. We would also like to thank all the patients, patient representatives and project co-ordinators who have contributed their views and experience. We appreciate their enthusiasm and support for Value+.

We hope that this comprehensive toolkit will help you through providing guidance and examples to support your organisation and your member organisations in playing a more active role in EC co-funded projects. This will, in turn, contribute to more effective patient-centred and equitable healthcare systems in the European Union (EU).

Warmest regards,

A handwritten signature in blue ink, appearing to read 'A. Olauson', with a stylized flourish at the end.

Anders Olauson
EPF President



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Quick Reference – Where to find the Tools and Examples

This table provides a quick reference for tools and examples from Value+ and other projects or organisations.

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'Checklist for researchers wishing to recruit participants to their research opportunities through Asthma UK' (example)	Recruiting patients, information and support for patient involvement	93
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About This Toolkit





1.1 WHO WROTE THIS TOOLKIT?

This toolkit was produced by a team from the project Value+ 'Promoting Patients' Involvement in EU Supported Health-Related Projects'.

A unique feature of the Value+ project is that patient involvement has been researched and evaluated by patients themselves, rather than by academics.

The Value+ project started in February 2008 and ran to the end of January 2010. It was co-funded by the European Commission (EC) Public Health Programme, to support the exchange of information and experience on good practice relating to patient involvement in projects co-financed by the EC. From now on we refer to these projects as 'EC-funded projects', although the EC provides only a percentage of the funding.

The team came from a consortium led by the European Patients' Forum (EPF). EPF is an umbrella organisation of patient organisations in Europe. Most of the partners were patient organisations, and the consortium also included a research institute.

Each step of the research was planned and guided by a Steering Group with members from each of the consortium's partner organisations. A unique feature of the Value+ project is that patient involvement has been researched and evaluated by patients themselves, rather than by academics.

For this toolkit, the Value+ team gathered European, national, and local examples of good practice relating to patient involvement both in general, and specifically in health-related projects. We thank all those who have contributed information, examples, and references for this toolkit, and particularly those who took part in the Value+ focus groups and helped to develop the toolkit.

For more information on Value+, go to www.eu-patient.eu/projects/valueplus/index.php

For more information on the European Patients' Forum, go to www.eu-patient.eu/

1.2 WHAT IS MEANINGFUL PATIENT INVOLVEMENT?

The Value+ project was designed around the idea that when patients or patient representatives are involved in projects in a meaningful way, the results can contribute more effectively towards patient-centred, equitable healthcare throughout the European Union. Although the EC health policy already supports this idea, there is no direct strategy to make patient involvement in health-related projects a reality. Just as important, there is no consensus on what meaningful patient involvement means.

Patient involvement itself is generally taken to mean that patients take an active role in activities or decisions that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients.

The Value+ team built on this by asking what patients understood by 'patient involvement', and what had to be true for 'patient involvement' to be 'meaningful'. You will find a description and discussion of our findings in Chapter 2 Meaningful Patient Involvement.

Value+ researched patient involvement mainly through qualitative methods. These included:

- A literature review, relating to 'patient' and 'consumer' 'involvement' and 'participation', that included involvement in health policy and healthcare services as well as projects
- Questionnaires to health projects that have ended, which had been supported by the EC, and questionnaires to selected ongoing health projects, which were receiving EC support
- A focus group with patients and patient representatives from completed EC-funded health-related projects (the London focus group)
- A workshop of patients, patient representatives and project co-ordinators from ongoing EC-funded health-related projects (the Brussels workshop)
- A focus group of patient representatives and patients, some from ongoing EC-funded projects (the Berlin focus group)
- Interviews with representatives from selected projects
- Interviews with EC project officers
- Workshops held at European Patients' Forum events in Vilnius and Sofia.

1.3 WHO IS THE TOOLKIT FOR?

This toolkit is written for patient organisations, especially those who want to apply for funding for their own projects, or work with other partners on a [proposal](#) for EC funding. However the information will be useful for other patient involvement activities too. Some of the topics in this toolkit will also be useful to project co-ordinators and others responsible for organising patient involvement.

The main purposes of this toolkit are to:

- Support patient organisations in becoming involved in a meaningful way, particularly (but not exclusively) in EC-funded projects as project leaders or partners. This may mean increasing the skills within the organisation so that the organisation can expand its activities, that is, [capacity building](#)
- Give information about good practice in patient involvement
- Provide a definition of 'meaningful patient involvement'
- Provide a model for meaningful patient involvement in projects, and a way to evaluate involvement according to the model
- Support the planning of patient involvement from the beginning of a project or activity
- Support the evaluation of the quality and impact of patient involvement
- Explain why certain issues are more important to patients, so that project co-ordinators, health professionals and so on are more likely to plan patient involvement round these issues.

When groups of researchers and others are putting together project proposals, they often look to patient organisations to provide expertise on patient involvement and patient-related issues – and sometimes to provide the patients as well! The patient organisation may take on the role of communicating between researchers or project workers and [grassroots](#) patients.

The suggestions that patient organisations make about good practice in patient involvement can now be backed up by this toolkit. Patients throughout Europe have helped to define meaningful patient involvement, and the key elements of the Value+ Model of Meaningful Patient Involvement in projects. They have also contributed to this toolkit, and reviewed the contents.

1.4 WHAT IS IN THIS TOOLKIT?

The toolkit is divided into chapters covering several topics. Each chapter is divided into several sections. Below is a brief overview:

Meaningful Patient Involvement includes the Value+ research findings on the barriers and challenges to patient involvement and good practice in patient involvement.

Your Own Organisation and Meaningful Patient Involvement provides basic information which may help patient organisations prepare themselves for taking on an EC-funded project. It also includes good practice on managing patients who become involved as volunteers, rather than as paid workers.

European Projects gives information about the European Commission, and what to consider when putting together a proposal for an EC-funded project.

Working in Partnership provides guidance on how to find prospective [project partners](#), and how to build working partnerships with them.

Resources contains tools and examples from Value+ and other sources, examples of good practice, a list of websites, the Value+ Literature Review, a list of patient organisations that operate at European and national level, information on patient rights specific to individual countries, and national contacts for the European Commission.

Glossary contains an explanation for some of the words used in this toolkit, including some EC relating to projects.

We have chosen these topics after consultation with patients and patient representatives. In this toolkit we have sometimes emphasised important messages by talking to the reader, who we assume to be someone in a patient organisation – member, worker, Board Member, volunteer – directly as 'you'. We believe this may also make the toolkit easier to read for those whose native language is not English.

Within the Value+ project, we have used the term patient representative to refer to anyone from a patient organisation who represents patients, whether they were a paid worker or volunteer, with or without personal or family experience of the condition connected with their organisation. Of course many patient representatives are also patients. We have used the term 'patient' only for those who have been involved directly in a project as patients or as their family members, without being part of a patient organisation.



We discuss the issue of representativeness further in Section 2.4.1.

For a full list of the contents, see the Table of Contents, page 4.

For an overview of where to find specific issues, see the Quick Reference – Where to find the Tools and Examples, page, 7.

1.5 HOW TO USE THE TOOLKIT

All the topic chapters contain a short discussion of the main issues. There are many examples of the creative ways in which patient organisations have found answers to specific difficulties. Any tools relating to the topic, such as checklists, are named and described in the text; the tool itself will be found in the Resources chapter.

The 'Quick Reference – Where to find the Tools and Examples' table at the front of the toolkit should help you find exactly what you need.

Words which are included in the glossary appear underlined when they are first used in the text. We flag out some key terms more than once.

If you are using an electronic copy of this toolkit, you will be able to click a link to take you directly to the tool, resource or glossary entry.

We hope that this approach will help you dip into the toolkit to find quickly the topics and tools that you need. Do browse through the chapters as well, or you may miss something interesting!

Patient organisations throughout the EU are very different from each other, and so are European health-related projects. They take place in countries with different traditions and cultures and have different contents, objectives and goals. Patient organisations may therefore need to adapt some tools so that they are most suitable for their own needs.

1.6 A NOTE ABOUT LANGUAGE

Language presents a difficulty in patient involvement. Sometimes clinicians, academics and managers use a level of technical language which is not easily understood by a patient or patient representative. In the United Kingdom there is guidance available on using clear language when writing about medical topics.

However this toolkit is not just for native English speakers. Many of the people using an English version will be reading it as a foreign language. English is often used within the EU, and many foreign speakers are comfortable with a more technical level of language than native English speakers. This is because they have learned that sort of language through their work. They may not know the more informal words. Often they don't know that one word is more 'politically correct' or culturally appropriate than another.

This toolkit has been written with a commitment to being accessible to our intended readers, throughout the EU. We hope some readers will have access to a translation in their own language, but this will not be possible for everyone immediately. To make sure that the toolkit is easy to understand for our intended audience, we have asked many people of different nationalities for their feedback, and we have sometimes used words which would not be the first choice for native English speakers.

For example, we have referred throughout to 'patients'. The Value+ team has focussed only on projects relating to patients with chronic or recurrent conditions, however the word 'patient' can apply to anyone receiving healthcare. We know some people would never use the word 'patient' about themselves. They might prefer 'consumer of health services', 'client', 'service user' or 'survivor'. However we do believe that they, in common with millions of others in the EU, will understand what the word 'patient' means. We also believe they will share our commitment to making this toolkit accessible across Europe, and therefore be tolerant of language differences.

1.7 PATIENTS ADDING VALUE TO POLICY, PROJECTS AND SERVICES

The enthusiasm and motivation of patients and patient representatives has been a strong feature of all the Value+ focus groups and events. Whatever their level of knowledge, whatever the other skills, competencies and life experience they bring to patient involvement, they share a commitment to improving the healthcare and social circumstances of patients.

Patient organisations themselves are a direct result of this shared commitment; they have been created by patients and their families coming together to work for improvements. There has been enough motivation and energy for many patient organisations to look outside the boundaries of their own conditions and work co-operatively with other patient organisations at national or international level. The examples of good practice in Section 6.2 are some examples of what patients, through their patient organisations, can achieve, working in European projects to make a difference for grassroots patients.

However the Value+ project has shown that few health-related projects currently supported by the EC have a high level of patient involvement. This means that the enthusiasm and strong motivation of patient organisations, as well as the patients' unique perspective, are underused resources in building a Europe for patients. This toolkit provides guidance and examples of good practice to support patient involvement in general and in projects and policy in particular.

We hope that this support will be matched by a European Commission strategy to promote the involvement of patient organisations in EC-funded projects.

Meaningful Patient Involvement





2.1 CHAPTER OVERVIEW

This chapter contains many of the Value+ research findings. We describe the barriers and challenges to patient involvement, and examples of good practice identified in our research, then discuss good practice in representing patients. We talk about marginalised groups and discrimination in relation to health issues and patient involvement, then present our findings relating to gender and make suggestions for good practice in relation to the gender dimension.

Patient involvement is about patients and patient representatives being active in developing quality healthcare which meets patients' needs. The gender dimension looks at these issues from both the male and the female perspective, to ensure that particular needs are not overlooked. Marginalised groups are people on the edge of society whose needs are often overlooked, and their voices not heard.

We then present Value+ definition of meaningful patient involvement; this has developed from our direct work with patients and patient organisations. We have also built a model for meaningful patient involvement in projects, and developed a measuring tool to assess meaningful patient involvement.

The Value+ team has consulted extensively with patient organisations to be sure that the definition and the model reflect what patient organisations really think about patient involvement.

2.2 THE VALUE+ RESEARCH

Value+ research methods are described in Section 1.2. The sequence of the Value+ project activities was planned and recorded on a Gantt chart. This chart shows how the activities throughout the project contributed to the development of this toolkit, the handbook, our recommendations to the European institutions, and other deliverables. We include this chart for information about the Value+ project, and as an example of a project planning tool.

For the Gantt chart of the Value+ project, go to Section 6.3.

In this section we include some information about patient involvement from the Value+ Literature Review, and we relate this information to what we found out directly from current or recently completed EC-funded projects. Our findings about the benefits, barriers, and challenges to patient involvement follow in the next section. In general, the information gathered from the projects matched well with the findings of our literature review.

An outstanding feature of the projects we researched was their diversity. Project aims included:

- Developing and trialling education packages for patients – how to cope better with their condition
- Educating health professionals and patients together
- Challenging stigma – health education for the public and employers
- Developing and trialling new treatments, including technological aids
- Setting up networks to establish treatment standards and ensure good practice
- Gathering data and developing policy recommendations for lobbying on health issues.

We believed patients could be involved in various roles at different project stages. The Value+ questionnaire sent to completed projects aimed to identify where and how patients or their representatives had been included in each project, as well as the projects' views on aspects of patient involvement.

The Value+ Steering Group also drew up criteria for meaningful patient involvement. Participants in the London focus group, at our event in Vilnius, and at the Brussels workshop added their comments about our criteria, leading to the development of the Value+ Indicators for Meaningful Patient Involvement. Participants at the Berlin focus group tested these indicators and other tools. Our definition and model of meaningful patient involvement were built on this work and we also developed a checklist for assessing patient involvement. We then consulted participants at our event in Sofia and many others who had attended previous events or had contact with Value+ in other ways also took the opportunity to comment. Some of these people contributed also to the development of the Value+ Policy Recommendations to the European Institutions.

In general, there was a lot of interest in the idea of meaningful patient involvement. Some questionnaire respondents asked themselves whether their patient involvement had been 'good enough' to qualify as 'meaningful'. Through this toolkit Value+ offers a framework for patients and projects to plan and evaluate their patient involvement. The process of planning patient involvement at the project proposal stage, then monitoring it during the project, is likely to identify areas where adjustments are desirable. Improvements can then be made during the life of the project.

At the moment there is no EC requirement to evaluate or report the amount or quality of patient involvement in an EC-funded health project. We believe that the Value+ quality indicators could be used for use for this purpose, when it is required.

Meaningful patient involvement is more than the number of patients involved, and the activities in which they have been involved. The assessment for qualitative indicators, for example, how satisfactory the involvement was, requires feedback from everyone involved in the project.

Patient involvement can be evaluated from the perspective of:

- The overall project
- The patient organisation and other project partners
- The individual patient.

All these perspectives are necessary for evaluating 'meaningful' patient involvement.

Our literature review discovered that three broad levels of patient involvement are recognised: consultative, participatory, and patient-led. We show how the main features of each type of involvement can be applied to projects using a chart entitled 'Value+ Levels of Patient Involvement in Projects'. We also suggest which of the Value+ Indicators are relevant at each level of involvement.

We believe that when patients and/or their representatives are involved only at the consultative level, their involvement cannot have an impact on the design of the project or how it is carried out. We do not recognise this as 'meaningful' involvement'. However, it can still be good quality involvement, measured by relevant indicators.

The Value+ team invited patients and patient representatives with experience in EC-funded projects to the Value+ focus groups and workshop; however, the people who attended also brought in experiences from other patient involvement activities. All these activities have contributed to this toolkit.

Patient involvement does not include being the subject of a study, for example taking part in a clinical trial, or simply responding to a questionnaire. It may be possible for projects which have patients as study subjects to develop patient involvement as well, with a patient organisation partner or individual patients taking other roles within the project.

Our literature review found that looking at levels of involvement can classify an involvement activity, but does not reflect the experience of individual patients. Over time an individual patient may take part in many involvement activities at different levels, and possibly more than one involvement activity at the same time. This experience enriches the patient organisations with which the patients have connections, and the projects in which they become involved.

It should be remembered that for individual patients, becoming involved is a personal choice. Many patients are content not to be involved directly, or only in less demanding or time-intensive tasks. Nevertheless, many patients and their families are supportive of the patient organisations' work in representing patients.

Go to Section 2.6.2 for Value+ definition of Meaningful Patient Involvement.

The Value+ Model of Meaningful Patient Involvement is fully described in Section 2.6.3.

Go to Section 2.6.4 for Value+ Indicators for Meaningful Patient Involvement.

For the Assessment Grid of the Value+ Model of Meaningful Patient Involvement in Projects go to Section 2.6.5.

See Section 2.6.6 for the Value+ Levels of Patient Involvement in Projects.

The Value+ Literature Review is in Section 6.6.



2.3 BENEFITS, BARRIERS, AND CHALLENGES TO PATIENT INVOLVEMENT

The Value+ research identified the following benefits of involvement, both practical and psychological:

Practical benefits for projects:

- Patients/patient organisations can bring funding
- A broader or different perspective is available, helping researchers understand the human aspect through patients' experience and expertise
- The right issues are addressed
- Knowledge of issues is more complete
- Good practices are validated by patients being involved
- Different objectives and more complete results can be achieved
- Patient involvement legitimises results; patient organisations make the results more widely available
- Communication becomes more patient-friendly
- The added drive of patient groups to lobby for implementation and sustainability of project results; patient organisations have a powerful voice.

Psychological benefits for patients and project partners:

- Patients have an opportunity to meet other patients and share coping strategies
- Patients have access to more information about the latest treatments and technologies
- Patients become empowered through finding a positive aspect to the condition they are managing, being valued for their expertise and skills, representing others and seeing the results of their work
- Patients' strong motivation encourages and supports other project partners.

Many of these benefits can be gained only when patient involvement is carried out well. Following a poor experience of patient involvement, patients and project partners may not wish to work together again.

“The personal experience and testimonials are more demonstrative and impressive than any scientific or statistical evidence (although I believe that both are needed). Patients are the experts of their own situation and thus nobody else can provide better knowledge and solutions to the challenges and needs they are facing”.

Project co-ordinator, 'Good Practices for Combating Social Exclusion of People with Mental Health Problems' project

Involving patients and patient organisations is not a quick and easy process. There are barriers and challenges to overcome first.

The Value+ Literature Review covered publications searching for consumer or patient involvement in health policy as well as health-related projects. Although the overall picture differs from country to country, the review identified legal, policy, and regulatory barriers to patient involvement. Some countries do not have a patient involvement culture, and do not always consider that patients' opinions are relevant. There were language and communication difficulties between patient organisations, grassroots patients and health professionals and/or policy makers. In many countries the literature shows that there is a lack of knowledge and mechanisms for planning, implementing, and evaluating patient involvement, and a lack of clarity about what patient involvement means. Bureaucracy and lack of resources are further barriers.

Value+ questionnaires, focus groups, and the workshop which included patient representatives and project co-ordinators, concentrated on finding out more about EC-funded health-related projects. These participants were strongly motivated to learn from each other and to find out about good practice in patient involvement. This was another indication that information on good practice in patient involvement in projects is not easily available everywhere.

The participants identified similar barriers and challenges to patient involvement, adding detail to the issues found through the literature review. They also identified additional issues, including some relating only to EC-funded projects, and others relating specifically to the involvement of individual patients. We describe these below:

- **Attitudes** – some experts do not consider patient organisations as credible partners, and this attitude may be stronger or more frequent in research projects. Some health professionals are resistant to patient involvement, and some patients and patient organisations are suspicious of some medical research.
- **Lack of clarity** – the term 'patient involvement' is used in different ways, not making clear whether it refers to the involvement of patients as individuals or the involvement of patient organisations. 'Patient representative' is another unclear term – does it refer to patient organisations, or relatives, or someone else?

- **Lack of knowledge** – project co-ordinators in particular felt they would like guidance on the tasks that patient organisations could carry out; this could be particularly helpful for research projects. Simply finding a patient organisation to work with could be a difficult task. Patient organisations themselves might lack knowledge about funding programmes, and about how to become a partner in an EC-funded project.
- **Language and communication** – languages may represent a barrier to the involvement of patients in EC-funded projects, as project information, and later the project results, are often available only in English. Communication from the ongoing project through the patient organisations to the level of grassroots patients, so that the grassroots patients are motivated to be involved and give feedback, could be difficult, particularly with very technical subjects.
- **Lack of resources** – patient organisations struggle to find the resources both for the work in preparing a project proposal, and for the co-funding necessary to become a partner in an EC-funded project. Adequate resources are needed to support patient organisations' communication channels with grassroots patients, for the translation of project information and results, for the expenses of attending meetings, and so on. Some expenses will be larger than might be expected because some patients are unable to use cheaper forms of transport, or need someone to travel with them. Resources are also required to pay individual patients for the tasks they do. Lack of payment prevents many patients from becoming involved at all. Patient organisations need resources to support volunteers; when projects involve patient volunteers directly, without a patient organisation partner, support for volunteers working in the project may be overlooked.
- **Bureaucracy** – the administrative procedures for project applications and the financial and technical reporting for EC-funded projects are complicated, and project partners are not allowed to sub-contract any of this work to a specialist. This might be particularly challenging for patient organisations with little experience and skills in working on EC-funded projects.

The participants identified that individual patients may be discouraged from becoming involved by:

- Needing time to come to terms with their diagnosis before they can become involved
- Sometimes, a lack of self-confidence
- Stigma associated with their condition
- Financial considerations, and whether the involvement can be paid

- Personal circumstances, including where they live, and family circumstances
- Their health status
- The need for an available person to go with them to meetings, and resources to pay that person
- The patient's time availability and the time scale of the project
- Not seeing the direct benefit to themselves or when that benefit will arrive
- 'Involvement fatigue' – those patients who are willing to be involved are sometimes worn out by the demands made on them, or the intensity of the activities required.

Involving patients well takes time and resources. Involvement is often a voluntary activity, rather than a full-time job. Patients may need longer than others in the project to fit in a task because of their paid employment commitments, treatment schedules or other personal circumstances. Time must also be allowed when patient representatives need two-way communication with grassroots patients to complete a task, particularly when those grassroots patients do not use email. Daytime meetings can be difficult for patients who are working. When project partners have a commitment to patient involvement, they need to allow for these issues in the project planning.

When researchers approach a patient organisation for help in recruiting patients for studies or involvement opportunities, they often find that they must meet the patient organisation's own ethical criteria.

The focus groups also identified that ethical issues can be a challenge. Applying for ethical permission is complicated, and procedures are aimed at health professionals working with patients on their treatment and care, particularly in clinical trials. The procedures are not designed for organisations which have no input into a person's treatment or care, but which wish to work with individual patients or groups of patients. At the same time, patients are concerned about ethical issues which are not covered by the official ethical permission. Patient organisations therefore use their own ethical checks when they are asked for assistance in recruiting patients. We include an example from Asthma UK.

For Asthma UK's 'Checklist for researchers wishing to recruit participants to their research opportunities through Asthma UK', go to Section 6.4.



A notable feature of the focus groups was the strong motivation of the patients and patient representatives who attended. Despite identifying so many barriers and challenges, they strongly supported the benefits of patient involvement. They identified good practices and made clear recommendations on how to get the most benefit from patient involvement.

Although it is not possible to provide answers for all the barriers and challenges, the Value+ project has collected information about patient involvement, and identified information sources, examples and tools which support good practice. We have developed tools to help with some of the more practical challenges. All this information and the tools are included in this toolkit. The Value+ Database of EC-funded projects which have included patient involvement will be a further source of information.

The Value+ Handbook for Project Co-ordinators provides guidance on overcoming other barriers. The Value+ project will also make policy recommendations to the European Commission calling for measures that will support patient involvement; these recommendations include waiving the requirement to find co-funding.

For the full Value+ Policy Recommendations to the European Institutions see Section 6.3.

For the database go to:
www.eu-patient.eu/projects/valueplus/database

Examples of how barriers can be overcome and challenges met are provided throughout this toolkit. For the specific topics see the table below:

Overcoming challenges and barriers to patient involvement in the Value+ Toolkit

Barrier	Toolkit section
Lack of information and knowledge on funding programmes	Section 4.2
Lack of information on how to become a partner in projects	Section 4.6
Finding patients or patient organisations who are truly representative of the patient group whom the project is intended to help	Section 4.3, 5.5, 6.3
Language and communication, including technological barriers	Section 2.4
The bureaucracy involved in preparing a project proposal and running a project to EC requirements	Section 4
Stigma associated with ill-health, which discourages patients from activities which identify them as having a condition	Section 3.5.2
Patients are not always seen as representative, or capable of taking responsible roles	Section 3.5.3
Medical resistance to patient involvement and patient suspicion of medical research	Section 5.3
Consistency during the project – a representative may change, or the group may change, owing to their personal health and circumstances	Section 3.5.4, Section 5.4
Good practice in involving patients as volunteers	Section 3.5

2.4 GOOD PRACTICE IN PATIENT INVOLVEMENT

The Value+ Literature Review identified six areas that support patient involvement:

1. Developing evidence-based knowledge
2. Lobbying health policy makers
3. Working in alliances with other patients representative groups and relevant stakeholders
4. Involving patients in consultation processes
5. Developing financial, structural and institutional support for patient involvement
6. Working within a context of equal power relationships.

The information, collected by Value+ from patients, patient representatives and project co-ordinators, shows their detailed perspective on these six areas, and includes their recommendations and examples of good practice.

1. Developing evidence-based knowledge

Focus groups and questionnaire respondents recognised the value of involving patients. Good quality patient involvement ensures that patient needs have been identified correctly, and that the planned project can meet those needs. Being able to represent patients, and making policy makers and health professionals more sensitive to patients' needs and the needs of marginalised groups, is a significant factor in patient motivation to become involved in a project.

2. Lobbying health policy makers

Focus group participants felt that influencing policy makers to change policy was the hardest project outcome to achieve. They recognised the value of working with other organisations to achieve policy change, and linking with other patient organisations or projects to strengthen the patient voice. When patients and project co-ordinators from current projects attended the Value+ focus group in Brussels, a strong motivation for their attendance was the opportunity to feed back to the EC on what EC-funded projects need to support patient involvement more effectively.

Patient organisations in Cyprus have lobbied politicians together. Their results include cheaper medicines and more employment opportunities for patients.

3. Working in alliances with other patient representative groups and relevant stakeholders

Many suggestions for good practice came from the focus groups. These included linking with other patient organisations, joining up with politicians, liaising regularly with health professionals, and involving health professionals in the work of patient organisations. Collaboration on planning a project proposal might include financial collaboration and sharing resources. Partnership and equality were felt to be essential for meaningful involvement of patients.

The patient organisation IPOPI has developed guidance for doctors on how to talk to newly-diagnosed patients.

Participants also referred to the special role of patient organisations as a bridge between project co-ordinators and grassroots patients, in ensuring good communication, including rewriting medical information from scientific language into everyday language. Some patient organisations have developed guidelines for clinicians on communicating with patients about specific conditions.

4. Involvement in consultation processes

Patient organisations' contacts with grassroots patients mean they can find out patient priorities, send out information, test and validate project results, and get rapid feedback. Care needs to be taken that feedback is two-way. Being consulted should be a positive experience rather than a discouraging one. In one focus group, one third of the patients/patient representatives said that the worst thing about being involved in a project was not being informed about the outcomes and impact of that project.

A patient group working with a health authority in the UK has produced its own feedback form, so that patient experiences of being involved can be monitored.

5. Financial, structural and institutional support

Good quality patient involvement requires funding. Lack of funding may limit the translation of information for patients, either into accessible formats or other languages, and thus restrict the scope of the project or the diversity of the patients involved. Translation into different languages is a particular challenge for EC health-related projects. It was felt to be an area where some centralised EC support could be provided.



Patients and patient organisations are usually, but not always repaid for their costs in becoming involved. Our focus group participants recognised that patient organisations need funds which allow them to keep their independence. Most, but not all, also felt that individual patients' expertise should be recognised by being paid for their time.

Information events and other activities which involve the public can support involvement by raising awareness of involvement opportunities, and by decreasing stigma. Focus group participants suggested that events and involvement opportunities should take place at a local or regional level, so that patients have more opportunity to be involved. Such events can be organised by patient organisations or by health authorities.

Benefits such as training can support patient involvement and act as an incentive to patients to become involved. Training may be provided by health authorities to develop a pool of skilled patients willing to be involved, or by patient organisations or projects for specific tasks. Some training may be aimed specifically at people from marginalised groups.

The value of personal contact in reaching grassroots patients, and of having a liaison person within the project whom patients can contact, was raised several times. Recognising patients' other time commitments, and planning the project timescale to allow for them is another important support that can be planned into the structure of a project.

The Treat-NMD project has a designated contact person for patients.

6. Working within a context of equal power relationships

Equal partnerships were generally recognised as the way forward, with many practical examples of how this ideal can be applied in a project.

Everyone in a project is likely to have a different background. Differences in gender, ethnicity, education, socio-economic status, age, and so on, have an impact on how people work together. Patient representatives sometimes find that they are ignored in project meetings, and have to work hard to be heard. Some female patient representatives believe this is a gender issue rather than a patient issue.

Gender is a problem in patient involvement, with most scientists being male and most patient representatives being female, this is part of the attitude to patient involvement.

Value+ focus group participant

Coaching and training for project co-ordinators, patients, and other project partners can support equal partnerships. Learning can be mutual and two-way, with patients delivering training as well as receiving it from other partners.

Patients and patient organisations should be involved from the beginning, in all areas of the project, including project management and writing and delivering the project report. Patient organisations and others who involve patients should identify the expertise of individual patients, and build on their strengths and professional skills. Patients then feel needed for their skills, and the focus is taken away from their medical condition.

Involvement should be rewarded. This can happen through financial payments. Not every patient wants to accept a payment, but offering it can be an important way to recognise patient expertise. Payments should be linked with a clear description of the role, and how the patient should carry it out. For example, a patient who has accepted the role of representing other patients should have two-way communication with grassroots patients and put their range of opinions forward, rather than just giving their own opinion. Rewards other than payment may include the opportunity to learn or practice skills.

Partnership between patients, patient organisations and other project partners should be recognised as a Win-Win situation. Acknowledgement of patients' work and its impact, both in the project report and at dissemination events, is essential.

2.4.1 GOOD PRACTICE IN REPRESENTING PATIENTS

Patient involvement is sometimes criticised on the grounds that the patients who become involved do not really represent grassroots patients. In this section we describe how we have used the term ‘patient representative’ during the Value+ project, and discuss some of the issues in representing patients.

In its research, the Value+ project has involved patients and patient representatives, mostly from EC-funded projects, and some from national associations. We have used the term ‘patient’ only for those patients who have been involved directly in a project, without being part of a patient organisation. We have used the term ‘patient representative’ for anyone from a patient organisation, whether paid worker or volunteer. Not all paid workers in patient organisations have personal or family experience of the condition their organisation represents, but many of them do. Volunteers we met were always patients themselves or family members of patients with the condition.

In our definition of ‘patient representative’, the Value+ research has not taken into account the difference between patients and patients’ family members or carers. We do recognise that patient and family/carer interests are often the same; they would both be affected by the price of medicines, for example. Their interests can also be different. For example, a family or carer may wish to restrict the activities of a patient to reduce risk and make caring for them easier; the patient might prefer to widen their activities and take more risk to find out if their condition will allow them to do more. For this reason, there can be tension between patients and family/carers, and patients may prefer to represent themselves rather than be represented by family/carers.

Many of the documents reviewed for the literature review did not make a strong distinction between patient and family involvement.

It was not essential to highlight the difference between patient involvement and family/carer involvement for the Value+ research. For some involvement activities it may be important to identify patient and carer perspectives separately. An example might be a consultation that seeks to identify the support needs of carers.

Much literature about patient involvement is written in English. It is important to understand that in English the term ‘representative’ can be used in two ways:

- Someone who is chosen to represent others
- Someone who is typical of a particular group of people.

When deciding to involve patients, it is essential to be clear whether you want a representative who will put forward the views of a group, or someone who is typical of a group but who will speak from their own views.

If you want someone to put forward views for a group, you should ensure that the person or organisation has a communication structure that will support the work you want. The queries received by a patient organisation usually provide their representatives with a good overview of the issues affecting patients with a certain condition, and they usually have a structure to get information out to grassroots patients.

If you want a patient who puts forward views based on their own experiences, you should ensure that their experience is relevant to your task. An individual patient has deeper knowledge of their own condition, but may not understand how the same condition affects other patients whose personal circumstances and background are different, or who are at a different stage of the condition.

Health factors may discourage patients from becoming involved. Value+ focus group participants suggested that involvement should be possible in a number of ways, without a patient always having to travel to meetings.

People wishing to involve patients may face difficulty due to the patients’ health issues and in some cases, the patients do not have enough mental capacity (this is a legal description of their ability to make and communicate decisions). In some circumstances patients themselves can only be represented through family and carers, rather than being involved directly; examples include patients with advanced dementia, and young children. The Value+ research has identified several projects, including Lawnet and Treat-NMD, which could not have taken place without the efforts of family and carers. Our focus group and workshop participants emphasised that patients’ relatives should also play an important role in projects with patient involvement.

All types of patients may be interested in contributing to improving healthcare, even though what they can do is limited. People setting up patient involvement should consider whether this is possible rather than automatically deciding to involve family representatives instead. The ‘Association Autism’ in Bulgaria has successfully involved patients with autism in its activities.



2.5 DIVERSITY ISSUES AND THE GENDER DIMENSION

This section describes the Value+ research on the gender dimension, some of the background to patient involvement and the gender dimension from a patient perspective, and our recommendations which result from the research.

People do not always recognise that women's and men's experience of their health is more than a reflection of their biological makeup, there is a social dimension as well.

One striking result of this part of the research were the many other discrimination issues raised, particularly by our focus group participants. They identified age, disability, ethnicity, sexuality, self-harm, alcohol, drug, and tobacco use, as factors which could affect patients' access to suitable health services. They told us that gender was not the only aspect of discrimination that should be researched. We have recognised their concerns in the title of this section.

2.5.1 WHAT DO PATIENT INVOLVEMENT, GENDER, AND DIVERSITY ISSUES HAVE IN COMMON?

People in the disability movement, patients campaigning for the right to involvement, and people campaigning for gender equality have much in common. They have all struggled to be recognised. Their ultimate purpose has been to gain rights and provision for their different needs. First they struggle to be heard, and then they struggle to show that they have different needs. They have experienced marginalisation. Marginalisation means that a group of people is treated as if they were not important.

Easy or not (it) is necessary to involve patients in the work of the organisations and in the process of healthcare policy making and teach them to act as self advocates.
Project co-ordinator Association Autism

Patient voices, however loud, have often been ignored, that is, patients are 'marginalised' and have not been encouraged to have an influence. Health professionals and policy makers may believe that patients do not have enough medical knowledge to be involved in health policy or projects, and may not recognise them as 'experts by experience'. When people promote the gender perspective, they may receive a similar reaction, that is, that gender issues are not important.

Patients may see patient involvement as an opportunity to reduce this marginalisation. When they become involved in health-related projects, their motivation includes improving healthcare, and reducing inequalities in the treatments available. Patients want their involvement to result in change – either in treatments, or the way they are delivered, to make them suitable and accessible for particular groups. They attach value to the patient's subjective experience.

The European Medicine Agency (EMA), and the Federal Drug Agency (FDA) in the United States sometimes allow patients to tell their experience of a treatment during a hearing. (This provides) extra illustrative information that can't be given by the scientifically gathered (clinical) data.
EC project co-ordinator

These values clash with traditional scientific methods, which aim to gather data in a value-free way, and see subjective information as a contamination of scientific data. Scientists may feel that patients' values fit more effectively with participatory, exploratory, and action-based forms of research. Patients are now challenging these scientific views, saying that it is impossible to gather information in a value-free way. Traditional scientific methods are not value-free, because scientists have decided to value particular types of information and exclude others.

Lack of awareness in the general population is a factor in marginalising any group. The Value+ project sent questionnaires out to project co-ordinators and patients involved in projects. We asked what was understood by the term 'patient involvement'. There was a wide range of answers. Some questionnaires showed very little knowledge of patient involvement or of sources of information on good practice in patient involvement. Responses to questions in the gender section often showed a similar lack of knowledge.

Patients from one Value+ focus group made a strong recommendation to patient organisations – "Don't support tokenism"!

Sometimes policy makers or funders require patient involvement or considerations for gender to be included in projects or other activities. If the people responsible for organising this don't know much about patient involvement or have little commitment to good practice, there is a danger of tokenism.

Tokenism means that just enough is done to tick a box to say a patient was involved, or gender was taken into consideration, but patient input is not allowed to have any real influence on the project or activity.

Both patient involvement and considerations for gender have changed position as a result of the struggle against marginalisation; they are now included in some political agendas. By achieving recognition, they are no longer completely marginalised ideas. There are real efforts to integrate patient and gender perspectives. However, these two terms can also become buzzwords.

Buzzwords are used in a similar way to herbs in cooking. Sometimes people hope that if they sprinkle enough buzzwords into their conversation – or herbs over the dish they are cooking, no-one will notice that they don't know what they are actually for. They even hope anyone watching may be impressed by their expertise, instead of noticing that they don't know how to cook. At least they are trying. Perhaps someone could give them this cookery book – sorry, we mean toolkit – to help them improve.

2.5.2 GENDER – THE CURRENT PICTURE

The European Commission recognises that there are inequalities related to gender, and requires the projects they support to take gender into consideration. However there are no guidelines or standards for good practice relating to gender. The Value+ researchers investigated what the EC requirement to consider gender issues has meant for patient involvement in projects.

The Value+ questionnaires sent out to completed projects included three gender-related questions:

- Did the project design take account of the differing project outcomes according to the gender of end users?
- What was the proportion of males and females amongst the patients/patient representatives involved in:
 - a. the design of the project?
 - b. the running of the project?
- Was taking account of gender differences useful for patient involvement?

Most respondents did not answer these questions. Some respondents did not understand the difference between sex and gender, and others felt it was unimportant or irrelevant. No one understood the question about project design relating to different outcomes for males and females. Only very few projects showed a clear gender dimension.

Women and men are different in regards to their biological make-up (sex). Gender is not related to biology; it refers to cultural issues: men and women's different roles and responsibilities in society, their access to and control over resources, including information, and their decision-making power.

Men's attitudes to health, and health behaviours, are different from women's. Health research in all areas shows that gender factors have a great influence on causes, consequences and management of diseases and ill-health. Prevention, treatment, rehabilitation and care delivery often need to be adapted to the gender of the people who will use them.

Usually projects had a gender balance of patients/patient representatives or else had a majority of women. There were a few exceptions where male patients were the majority.

Most respondents did not answer the question about whether taking account of gender differences was useful for patient involvement. The ones that did, said 'yes' or 'no' in equal numbers.

Value+ contacted projects and patient organisations and asked them to nominate patients or patient representatives for the focus groups; the participants were almost all women.

We concluded that male patients in particular are under-represented in EC-funded health-related projects. We believe that women and men should be encouraged to become equally involved in health matters that affect them, and that any gender bias in the recruitment of patients should be identified, and solutions found where possible.

We also concluded that there is a need for greater public understanding of the difference between sex and gender, and the relationship between gender and health inequalities. The European Men's Health Forum and the European Institute of Women's Health, partners in the Value+ project, developed a simple explanation of the difference between sex and gender, and how gender is relevant in health issues and patient involvement. At the Berlin focus group, participants described their current understanding of gender as it related to health issues. Then the simple explanation was tested in a short presentation.



Academics research gender a lot, and they talk about it in a complicated way that ordinary people don't understand. So gender is often used to refer to biological differences, and the real benefits of paying attention to gender are not recognised.

Value+ Gender Presentation

In describing their understanding of gender before the presentation, the participants identified several issues and examples which were contained in the presentation that followed. One female participant gave the following view:

"Most scientists are male and most patient representatives are female, and this is part of scientists' negative attitudes to patient involvement".

Despite identifying several issues, many participants did not consider gender as a priority for patient involvement. The reasons they gave were:

"Gender is not the only aspect of discrimination. Age and disability must be taken into account too".

"It is difficult to get patients involved".

"The amount of male involvement will change as society changes; this is happening now".

"The principle of involvement appeals more to women who are conditioned to think of others".

Following the presentation, all participants said it had changed their understanding. Most said it had altered their view of the importance of gender. One asked:

"50:50 representation (in a project) is not an accurate reflection for a disease that affects mostly women. Should gender representation be linked to the condition, the organisation, society at large, or reflect the gender balance in the medical profession, which is 80% male?"

Everyone remained unsure about what, in practice, they could do differently. We give some suggestions in this toolkit.

Go to Section 6.3 for the Value+ Gender and Patient Involvement in Health Projects Information Sheet.

2.5.3 GOOD PRACTICE WITH THE GENDER DIMENSION

Value+ identified that gender is not always understood or considered important for patient involvement. This may lead to missed opportunities to add perspectives from male or female patients/patient representatives in a project. Even when the importance of gender is recognised, it is still not clear what a patient organisation or project should do. The ideals of 'equality' and 'equal access' to patient involvement opportunities are more complex than a 50:50 gender ratio. It is good practice to involve a mix of male and female patients that reflects the number of men and women in the population affected by the health topic of the project.

Academics find gender is a powerful concept to work with. It may be harder for people who have not had specialised training. Gender relates to culturally determined behaviours and attitudes, and these vary between communities, age groups, and geographical location. These also change as time passes. Because of this variation, exceptions can usually be found to statements about gender behaviour or attitudes. People may prefer to avoid the topic of gender in case what they say is perceived as wrong, or is not well received.

A project about endometriosis should involve women primarily. It should not however exclude men (not least because they can be carers and family members affected indirectly by the condition). And vice-versa, say for a prostate cancer-related project.

European Institute of Women's Health

People need a good understanding of gender to work with the gender concept. They also need the ability to stand back and listen to what is being said without getting angry. Discussions about gender can trigger strong emotions!

The European Men's Health Forum and the European Institute of Women's Health suggest the following indicators for working with gender:

- Both men and women must be involved actively to generate a rich and relevant mix of approaches to health matters. They should be involved equally at all stages of project development and implementation
- Meaningful participation opportunities should take account of gender differences. For example, women and men often need to be approached and involved differently
- Male and female participation should be appropriate to the gender dimension of project objectives and outcomes.

When women or men participate as study subjects, the relative or carer perspective should also be included in advisory roles, for example in clinical trials with sex specific diseases, such as cervical or prostate cancer.

Gender Issues in Health – Some Examples

The public and health professions often assume that cardiovascular disease mainly affects men. Most research is based on studies of men. However, cardiovascular disease is the number one killer of women, and women can find it difficult to get the right diagnosis and treatment.

Men tend to delay seeking health advice when they feel unwell. They need to be approached specifically regarding their involvement in health matters, because they see health as a matter for women.

Cultural heritage may restrict women's access to health services and in some cultures they may only be permitted to see a female doctor.

2.5.4 GOOD PRACTICE WITH DIVERSITY

Gender is a universal factor. All people, and therefore patients have a gender, and gender goes across all other dimensions. There are similarities between women's behaviour and attitudes, and men's behaviour and attitudes, across socio-economic, religious, cultural, ethnic, and other, categories.

We will never be truly representative
but every communication should
a) demonstrate what shortcomings
there may be in representation and
b) explain how/whether effort has been made
to correct this.

Europrevall project

The Value+ project researched the impact of gender considerations on patient involvement because of the EC requirement for gender inclusion in projects. However the gender perspective needs to be considered alongside other diversity issues.

Marginalisation can affect people's access to health services, education, jobs, and many other opportunities which the majority of the population may take for granted. Some examples of marginalised groups could include ethnic groups, people who abuse alcohol or drugs, migrants or people in isolated communities. The groups that are marginalised and the efforts made to include them will be different in each Member State.

Although people from marginalised groups are all likely to be patients at some point in their lives, they may have the most difficulty in making their needs known, and the least opportunity for patient involvement, and indeed to be included in other aspects of their communities. If training opportunities to prepare patients for involvement tasks are made available in Member States, efforts should be made to ensure that a wide range of people can access these opportunities.

Beyond the Usual Suspects: Developing diversity in involvement is a project funded by the UK Department of Health. It aims to find out how more people can get involved in service user issues, and why certain groups of service users, such as younger people, people who communicate differently, people from black and ethnic minority communities and people using residential services, experience additional barriers to involvement. See www.shapingourlives.org.uk/dd2005.html



2.6 A MODEL AND INDICATORS FOR MEANINGFUL PATIENT INVOLVEMENT

2.6.1 INTRODUCTION

If you have a goal you will move in that direction, even if you do not get there quickly. If your partners do not have a standard to aim at, they probably will not wander in that direction by chance.

Value+ recognises that good practice in patient involvement requires time and resources. Some patient organisations have little funding and few or no paid workers. Good practice is an ideal, an aspiration – something to work towards, although it may not always be possible to achieve everything you want with the resources available.

We also see that project partners who are not patient organisations themselves often have little knowledge of patient involvement. We see that patient organisations have a role to play in educating health professionals, researchers, policy makers and civil servants about what patient involvement is. Value+ gives a definition for meaningful patient involvement and suggests a model for meaningful patient involvement in projects in which patient organisations are leaders or partners. We also suggest indicators and an assessment grid related to the key features of the model.

We are aware that some projects involve patients directly, without having a patient organisation as a project partner. We suggest that our indicators, where relevant to your project, can be used to support good practice also in this type of patient involvement. We refer the co-ordinators of those projects also to guidelines developed by the International Alliance of Patient Organisations (IAPO); these were written for any organisation wishing to involve patients or patient organisations. There is also a policy statement on patient involvement in the publication section of the IAPO website.

For the IAPO Guidelines on Patient Involvement, go to: www.patientsorganizations.org/showarticle.pl?id=591&n=962

2.6.2 THE DEFINITIONS

Because 'patient' and 'involvement' are common words, not everybody is aware that when they are put together they have a special meaning. They may confuse them with other things. For example, patient involvement is not the same as:

- Being a study subject, for example in a clinical trial or through responding to a questionnaire
- Patient-centred care, which is healthcare planned around patient needs rather than the needs of the health provider
- An individual's involvement in their own healthcare. Although patients in most European countries have a right to be involved in their own treatment decisions, this does not directly influence the treatments and healthcare available for others.

Patient Involvement is generally taken to mean that patients take an active role in activities or decisions that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients.

In light of this definition, patient organisations can be seen as a means developed by patients to support patient involvement. Because running an organisation is an ongoing activity, patient organisations can also be seen as an ongoing patient involvement activity in itself.

Value+ confirmed that patients and patient organisations are strongly motivated to help develop treatments and healthcare that really do meet patients' needs. Although patients are willing to give their time and effort, there are barriers and challenges to overcome and involvement is not always a satisfactory experience. For this reason, Value+ decided to research **meaningful** patient involvement.

Meaningful means having a meaning; its opposite is 'meaningless' – having no meaning. In our research we found that project co-ordinators, patient representatives and patients were anxious to find out what 'meaningful' meant, and concerned with whether their involvement was good enough to be considered 'meaningful'. Putting a spotlight on good practice and **the quality of involvement** in this way is a positive outcome for Value+.

Patients also recognised that participating in clinical trials and scientific studies requires motivation and effort, and puts the participants at personal risk. They wished to acknowledge this meaningful contribution by patients, even though it fell outside the Value+ definition of patient involvement.

We did not want to tell patients what meaningful involvement was; we wanted them to tell us what would make patient involvement meaningful. This definition was developed slowly during the Value+ research, with input from patients at Value+ focus groups and events. For patient involvement to be meaningful, Value+ realised it should be connected with the values and purposes of those patients or patient organisations who are involved.

Value+ therefore proposes the following definition, which has been widely accepted at our different events and through our various activities:

Meaningful Patient Involvement means that patients take an active role in activities or decisions that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients. The involvement must be planned, appropriately resourced, carried out, and evaluated, according to the values and purposes of:

- The participating patients or patient organisations
- Other participating organisations and funding bodies
- The quality of their experiences during the involvement activity.

This definition can apply to involvement of individual patients or patient organisations in participatory or patient-led activities. It cannot apply to any activity where patients have not been involved in the planning.

2.6.3 THE VALUE+ MODEL OF MEANINGFUL PATIENT INVOLVEMENT

The projects researched by Value+ have only three things in common; they have been supported by EC funding, they are health-related and they have involved patients. Despite this, our research shows strong agreement between patients and their representatives about the key areas which should be evaluated to indicate meaningful patient involvement. Value+ has used these key areas as a base model for patient organisations participating in projects with other partners, or leading their own projects. These key areas are supported by many indicators of good practice which will be described in Section 2.6.4.

The **key areas** are:

- Patients/patient representatives' involvement at the beginning and throughout the project in planning and decision making
- Co-operative working with other partners, supported by a clear understanding of each other's roles
- Providing information and support for patient involvement, including clear communication about the project itself
- Monitoring and evaluation of patient involvement from the perspective of all the partners
- Evaluation of the project's results and impact, identifying how patient involvement has enhanced the results.

Working from these key areas, Value+ has identified a model of patient involvement in projects for patient organisations. The model shows the values and purposes associated with the key areas, and methods which support them.

The Value+ Model of Meaningful Patient Involvement

1. Patients/patient representatives' involvement at the beginning and throughout the project in planning and decision making

Values: Respect for patients as equal partners, social inclusion of diverse groups, appropriate representation of patients

Purposes: Ensuring that the project working methods encourage full participation by all partners, that patient perspectives are fully understood, that project outcomes are improved by patient involvement, that the project takes account of gender and diversity issues

Methods: Patient organisations should work with prospective project partners to:

- Identify the project topic, or those aspects of the topic of most interest to their patients
- Identify what the special contribution of patients should be and how and where the patient organisation or grassroots patients can be involved most effectively
- Identify the specific patient groups or other patient representatives who should be involved, taking into account age, gender, ethnicity and so on



- Take part in developing and costing the detailed plans for these project activities, taking into account the requirements of their patients, for example, information in different language or formats, needing someone to accompany them to meetings
- Develop a strategy for communication between partners, and a strategy for supporting patient involvement
- Develop a strategy for monitoring and evaluating both the project itself, and patient involvement within the project.

If the project goes ahead with the patient organisation as a partner, the patient organisation should manage its own work areas and take part in the overall management of the project, making the strategies work.

2. Co-operative working with other partners, supported by a clear understanding of each other's roles

Values: Building on diversity and pooling knowledge to achieve more than can be achieved by each partner working alone

Purpose: Effective use of project resources and expertise

Methods: The partners' communication strategy should include:

- Induction and training for all partners about the other partners, their roles and special expertise
- Induction and training about the communication methods which will support both patient involvement and communication within the project
- Opportunities to build working relationships through formal and informal activities
- An agreement about how each partner can fully participate in project decisions
- An agreement about what should be presented at full project meetings, and which topics are better suited to specialised subgroups.

3. Providing information and support for involvement, including clear communication about the project

Values: Equality, providing an empowering environment for patients

Purpose: To enable patient organisations and patients to contribute fully to the project, and to be informed about the results of their involvement

Methods: The partners' strategy for supporting patient involvement should cover:

- The production of project information and project results in a patient-friendly format
- The recruitment and induction of grassroots patients
- Support and training for specific project tasks
- The patient organisation's support and mentoring for grassroots patients
- How to ensure continuity, if an individual patient has to drop out
- Acknowledgement of the contribution that patient involvement has made to the project
- The provision of information to patient organisations and grassroots patients after their involvement in the project has ended about the impact of the project results once the project is over.

4. Monitoring and evaluation of patient involvement from the perspective of all the partners

Values: Commitment to ensuring that patient involvement is a positive experience which adds value to the current project and can be built on in the future

Purpose: To identify difficulties and possible improvements during the project, and learn lessons for future initiatives

Methods: The monitoring strategy should include perspectives from:

- The patient organisation
- Grassroots patients
- Other project partners

and provide a check on:

- How representative the involved patients are, in terms of age, gender, disability, ethnicity, sexuality etc. of the patient groups which will be affected by the project outcomes
- How all partners experience patient involvement
- The contribution that patient involvement is making to the project results.

5. Evaluation of the project's results and impact, identifying how patient involvement has enhanced the results

Values: Respect for patients as equal partners

Purpose: Full recognition and acknowledgement of patient contribution, improving the status of patient involvement.

Methods: The evaluation should:

- Acknowledge patients' input
- Record the reasons for not involving the patient organisation or grassroots patients in particular tasks or work areas
- Record the reasons for including a patient representative rather than a patient
- Record the reasons for not including patient representatives of a particular patient group
- Describe how patient involvement shaped the project, and achieved more than a similar project without patient involvement could have done
- Include the impact of the involvement on the patient organisations, and on the other partners
- Include grassroots patients' own evaluations of their involvement
- Identify the impact of the project results on health policy, and quality of care.

2.6.4 INDICATORS FOR GOOD PRACTICE IN PATIENT INVOLVEMENT

This section looks at evaluation of meaningful patient involvement.

There are many indicators developed by patients to evaluate good practice in patient involvement; the IAPO guidelines described in Section 2.6.1 are an international example. The evaluation questionnaire 'How Did We Do When We Involved You!!' was developed by patients and carers from a local patient group in the UK to give feedback on involvement in local healthcare and policy. The User Focused Monitoring model developed by psychiatric patients and widely used in the UK may be useful as part of monitoring patient involvement within a project, particularly when grassroots patients are involved directly rather than through a patient organisation.

Go to Section 6.4 for 'How Did We Do When We Involved You!!'

For A Guide to User Focused Monitoring, see www.scmh.org.uk/publications/guide_to_UFM.aspx

The 17 indicators developed by the Value+ team follow the key areas on which the Value+ Model of Meaningful Patient Involvement is based. However they can be applied to patient involvement in a project or to any other involvement of patient organisations or grassroots patients. They may be particularly useful to project co-ordinators who are involving grassroots patients, without a patient organisation as a project partner.

These indicators have been developed into a more detailed Assessment Grid for projects which are planning patient involvement according to the Value+ Model.

Value+ Indicators for Meaningful Patient Involvement

Involvement in planning and decision making

1. Patients/Patient organisations helped to identify the topic addressed by the project
2. Patients/patient organisations helped to shape the project design
3. Meaningful patient involvement and its monitoring and evaluation during the project were part of the project design
4. The patients/patient organisations involved represented the type of patients who would be affected by the project outcomes.

Co-operative working with all partners

5. Project partners understood and supported patient involvement in the project
6. The patients/patient organisations were involved in the project Steering Group and felt they had an influence on the decisions made
7. The patients/patient organisations involved in the project Steering Group had two-way communication channels with grassroots patients, that enabled them to pass on information and receive feedback
8. Activities were carried out that would not have been possible without patients/patient organisations taking roles in the implementation of the project.



Support for involvement

9. Involvement was possible in a number of ways, and training or coaching was available for some aspects of involvement
10. Sufficient resources were available to support the work done by the patient organisations, other patient representatives and individual patients. The budget included patient expenses, and the costs of appropriate communication with grassroots patients
11. There was some continuity of involvement through all stages of the project, that is, the same patients or patient organisations contributed to planning and carrying out the project. Patient organisations provided support for grassroots patients and were able to ensure good handovers if patient representatives changed
12. Patients who had chosen to be involved in a 'one-off' activity were kept informed, in an appropriate way, of the project progress and about the project results and their impact after the project ended.

Monitoring and evaluation of patient involvement

13. The experience of patient involvement in this project has been positive for the patient organisation, individual grassroots patients, and other project partners
14. Adjustments could be made during the project because of the ongoing monitoring of patient involvement.

Evaluation of the project's results and impact

15. Results were obtained that would not have been possible without patient involvement; this was acknowledged in the project report
16. The experience of patient involvement in this project has strengthened the patient organisation's skills and/or improved its services to grassroots patients
17. The project outcomes can have a positive impact on grassroots patients, whether they were involved in the project or not.

2.6.5 ASSESSING MEANINGFUL PATIENT INVOLVEMENT USING THE VALUE+ MODEL

Value+ offers an assessment grid to evaluate meaningful patient involvement in projects which are following the Value+ Model. This grid is for internal use by the project, though the project partners may wish to find someone experienced in patient involvement to act as an external evaluator. We suggest that evaluations of patient involvement should take place at intervals through the project, so that adjustments can be made if wished. The evaluations should include perspectives from everyone in the project, not just patients.

We understand that it will not be possible to evaluate some indicators relating to the project impact until after the project has closed.

Currently there is no requirement to evaluate patient involvement in EC-funded projects. We hope that the Value+ Model and the assessment grid that goes with it will be adopted by the EC, and perhaps other funders. Those funders may add requirements, such as evaluation at proposed intervals during the project, or bringing in an evaluator from outside the project.

When funders adopt the Value+ Assessment Grid, or indeed any other method of evaluating the quality of patient involvement in projects, their project officers and evaluators will need adequate training so that they know what is expected of them.

When gender mainstreaming was adopted for EC projects, EC project officers did not receive training about gender. EC project officers and people making proposals for projects did not have enough information about what was expected of them. The Value+ research has shown that the gender perspective is not well understood within projects, and therefore the benefits of paying attention to the gender perspective are rarely showing through in projects.

Patient involvement could run the same risk if it is adopted as a requirement by funders, without adequate information and training for everyone concerned.

ASSESSMENT GRID OF THE VALUE+ MODEL OF MEANINGFUL PATIENT INVOLVEMENT IN PROJECTS

Scoring the Grid

Met means that the indicator has been met in full

Partly met means that some effort was made to meet the indicator, but that it was not met in full

Not met means that the project did not try to address the topic of the indicator

Please note that the model requires support for patient involvement to be planned into the project design. Much of the support for patient involvement is therefore assessed under that heading.

Indicator	Met (2)	Partly met (1)	Not met (0)
Patients/patient representatives' involvement at the beginning and throughout the project in planning and decision making			
Patient organisations identified the project topic, or those aspects of the topic of most interest to their patients			
All project partners were involved in identifying what the special contribution of patients should be, and how and where the patient organisations or grassroots patients could most effectively be involved			
The patients or patient organisations involved represented the type of patients who would be affected by the project outcomes, taking into account gender, ethnicity, age, etc.			
Meaningful patient involvement and its monitoring and evaluation during the project were part of the project design			
Patients or patient organisations took part in developing and costing the detailed plans for project activities where patients would be involved, taking into account patients' special requirements, for example, information in different language or formats, needing someone to accompany them to meetings			
The project plan included a strategy for communication between partners, and a strategy for supporting patient involvement			
Maximum Score: 12 Total:			
Co-operative working between patients/patient organisations and other partners, supported by a clear understanding of each other's roles			
There was an induction and training for all partners about the other partners, their roles and special expertise			
There was induction and training about the communication methods which would support both patient involvement and communication within the project			
There was an agreement about how each partner would fully participate in project decisions, about what should be presented at full project meetings, and which topics were better suited to specialised subgroups			
There were opportunities to build working relationships through formal and informal activities			
Maximum Score: 8 Total:			



Indicator	Met (2)	Partly met (1)	Not met (0)
Providing information and support for involvement, including clear communication about the project itself			
There were resources for the recruitment, induction, support and expenses of grassroots patients, as well as training for specific project tasks			
The project plan allowed adequate time and resources for appropriate communication with grassroots patients			
Patient organisations provided mentoring for individual patients, and ensured continuity if a patient had to leave the project			
Grassroots patients were kept informed about the project after their involvement in the project had ended, and about the impact of the project results after the project was over			
The contribution made by patient involvement to the project was acknowledged with appropriate detail in the project results			
Maximum Score: 10 Total:			
Monitoring and evaluation of patient involvement from the perspective of all the partners			
There was a check on how representative the involved patients were, in terms of age, gender, disability, ethnicity, sexuality etc. of the patient groups who would be affected by the project outcomes. If it was not possible to involve a particular group, the reasons were recorded			
Perspectives about patient involvement in the project were obtained from all project partners, not just patients or patient organisations			
It was possible to identify the specific contribution made by the patient organisations and grassroots patients			
Adjustments could be made during the project because of the ongoing monitoring of patient involvement			
Maximum Score: 8 Total:			
Evaluation of the project's results and impact, identifying how patient involvement has enhanced the results			
The evaluation described how patient involvement shaped the project, and achieved more than a similar project without patient involvement could have done			
The evaluation recorded the reasons for not involving the patient organisation or grassroots patients in particular tasks or work areas			
The evaluation recorded the reasons for including a patient representative rather than a patient, and for not including patients who were representative of a particular patient group			
The evaluation included the impact of the involvement on the patient organisations, and on the other partners			
The evaluation identified the impact of the project results on health policy			
Maximum Score: 10 Total:			

Meaningful Patient Involvement

Indicator	Met (2)	Partly met (1)	Not met (0)
Planning and decision making			
Co-operative working			
Support for Involvement			
Evaluation of Involvement			
Evaluation of Project			
Maximum Score: 48 Your score:			

You might find useful to reflect on your score by looking at the table Value+ Levels of Patient Involvement in Projects on the next page.



Value+ Levels of Patient Involvement in Projects

TYPE OF INVOLVEMENT	VALUES AND ATTITUDES	ADVANTAGES	DISADVANTAGES
CONSULTATIVE			
<ul style="list-style-type: none"> Patients are involved in research or project stages by consultation, (for example evaluating a proposal, or commenting on the design for a questionnaire) Patients are not involved in carrying out the project. 	<ul style="list-style-type: none"> Valid outcomes sought according to scientific methods Personal experience may be seen as irrelevant to scientific study, and possibly lowering the quality of research. 	<ul style="list-style-type: none"> For project teams: Quick Less costly Validation of results. For patients: Preferred by some patients Can raise awareness of health and research issues. 	<ul style="list-style-type: none"> For project teams: No ongoing patient review of the project work No patient support in disseminating results to patients. For patients: Length of time from consultation to publication of results can be frustrating for patients Individual patients frequently not informed of the results or their impact on policy.
PARTICIPATORY			
<ul style="list-style-type: none"> Project or research done with patients taking roles in carrying out the project Patient organisations may be project partners Involvement possible at all stages, including project design. 	<ul style="list-style-type: none"> Patients contribute more than just being 'subjects' Recognition of the patient's holistic experience and its value in research Emphasis on process as well as outcomes. 	<ul style="list-style-type: none"> For project teams: Patient experience can inform the project design Patient researchers can get different, qualitative information from patients Validation of results Wider dissemination of results, particularly to patients Additional lobbying power for policy change Improved relationships with patients and families. For patients: A positive aspect to the condition they are managing Seen in a more capable role by their care teams Opportunity to learn new skills Possibility of change and ideas into action Patient-friendly information on project results. 	<ul style="list-style-type: none"> For project teams: Finding patients with experience relevant to the project or research subject Additional cost and expenses – possibly including payment for patients' expertise Working with patients as equals rather than in a patient/health professional role can feel challenging. For patients: Involvement can be tokenistic – '<u>ticking the box</u>' Areas for genuine involvement may be limited.
PATIENT-CONTROLLED			
<p>Project actively controlled, managed and directed by patients/patient organisations.</p>	<ul style="list-style-type: none"> Commitment to addressing marginalisation Commitment to empowerment through project participation and output Project outcomes should lead to action/change. 	<ul style="list-style-type: none"> For project teams: <i>as for participatory projects and research</i> Validation of project/ research design. For patients: <i>as for participatory projects and research</i> Being in control of the project (and the research process if applicable). 	<ul style="list-style-type: none"> For project teams: Harder to get project funding if no academic partner. For patients: Harder for research results to be accepted by academics.

Your Own Organisation And Meaningful Patient Involvement





3.1 CHAPTER OVERVIEW

In this chapter we look at how a patient organisation can prepare itself for taking part in a project, with some detail on governance and management, and technology issues. Participants at Value+ focus groups and events have consistently highlighted the importance of communication so we include that topic too. Finally we discuss involving patients in patient organisations as volunteers.

Patient organisations and the projects they wish to take part in are diverse. Not everything in this chapter will be relevant to every organisation. Patients in small groups and international patient organisations will use this toolkit in different ways. Some descriptions of basic information and principles might be useful in training new volunteers. Just pick out the topics and tools that are relevant to you.

Good practice needs to begin at home. Your constructive suggestions to project partners for improving patient involvement will be easier to understand if you can show that the same ideas work in your own organisation.

3.2 WHAT IS A PATIENT ORGANISATION?

The definition of patient organisations used at EC level by the European Medicines Agency (EMA) is:

'Not-for profit organisations which are patient focused, and whereby patients and/or carers (the latter when patients are unable to represent themselves) represent a majority of members in governing bodies.

These could be:

- *either general umbrella organisations (e.g. representing either European specific disease organisations and/or national umbrella organisations)*
- *or European disease specific organisations (i.e. representing national organisations or individual patients on acute and/or chronic diseases)'.*

Patient organisations are usually run by a Board of volunteers elected by the members, and may be registered as not-for-profit organisations in their own countries. If the organisation is registered in this way, it means it must meet particular requirements.

These requirements vary by country. They include stating the purpose of the organisation, (sometimes called a mission statement), having a constitution or articles which make it clear how the organisation is governed, and making the organisation's accounts available to its members and the public.

Small local patient groups, which may have little organisational structure themselves, may become members of patient organisations and be supported by them to take part in national consultations, larger projects, and so on. Some small groups receive similar support from other organisations, such as health authorities or non-governmental organisations (NGOs) which are not patient organisations. These larger organisations can manage the administrative and financial aspects of the project, which might be beyond the capacity of a small informal group.

In order to receive significant funding, and to be credible in the policy environment whether at EC level or elsewhere, patient groups need to develop a structure that enables them to take on this kind of tasks themselves. This structure is usually called governance.

3.3 MANAGEMENT METHODS

This section covers governance, project management, and working in meetings. As with other topics in this chapter, we provide some basic information, then signpost our readers to other information sources.

3.3.1 GOVERNING A PATIENT ORGANISATION

It is recognised that an organisation's ability to survive through difficult times and continue its activities, that is, sustainability, are related to the quality of its governance – the systems and structures which support the organisation to carry out its work. For NGOs, the focus falls on the elected Board Members or Trustees. They are responsible for providing good leadership, planning and budgeting, recruiting any staff and supervising the Chief Executive Officer (CEO) if there is one, and making sure that the organisation complies with national law, for example, on Data Protection, Health and Safety, Employment.

In the UK, the National Council for Voluntary Organisations (NCVO) has produced 'Good Governance – A Code for the Voluntary and Community Sector'. This is written to support Board Members in community and voluntary groups of any size. There are other publications and resources of interest on the NCVO's website www.ncvo-vol.org.uk/.

The Global Forum on NGO Governance website <http://ngoboards.org/> has an online forum, and a resource section in several languages, including Eastern European languages. The resources describe the responsibilities of Board Members and their Chief Executive Officer, accountability, legal and ethical issues, and financial management.

In July 2009, 15 national umbrella organisations for NGOs in Austria, Cyprus, England, Estonia, Germany, Hungary, Latvia, Lithuania, Malta, Northern Ireland, Poland, Portugal, Romania, Scotland and Slovenia came together to form The European Network of National Associations (ENNA). The members of this network share good practice as well as concerns about the impact of the recession on voluntary organisations. ENNA will work to ensure that voluntary organisations are heard in the EU. At the time of writing there is no website.

3.3.2 MANAGING A PROJECT

The Board of a patient organisation has responsibility for the management of an organisation's activities, including any projects. The Board Members must ensure that there is enough capacity (working time of people with the necessary skills) and resources (money, equipment, specialist knowledge) for its activities. If the organisation is large enough to employ staff, some of the responsibilities may be delegated to the Chief Executive Officer, who in turn may delegate them to other staff. The responsibilities of staff members and their limits are described in job descriptions and employment contracts.

If the patient organisation has no permanent staff, it may still take part in projects by hiring self-employed workers whom they supervise. The Board would manage the funding and report to the funders. When the EC is providing funding, the EC Project Officer will explain to the project co-ordinator the requirements for reporting on the project and tracking the finances (see Section 4.10).

The project proposal should include a description of the project, divided into work packages, showing how the work packages will combine to produce the planned project outcomes. If more than one organisation is involved, as in EC-funded projects, the proposal also shows how the work is shared out between them, and how it will fit together.

If funding is granted, the lead partner will appoint a project co-ordinator to ensure that each part of the work is completed in time for the next stage, and to ensure good communication between the partners.

Four tools are often used in project management: Gantt charts, critical paths, risk logs, and budget projections. Excel spreadsheets are commonly used for these tools:

Gantt charts are used to plan and schedule the activities within a project. They show the order in which tasks need to take place and enable everyone to see how their part of the project can support – or delay – the work of others. The timeline runs along the top and the work packages down the side of the chart. The activities of the work packages are shown under their start and finish dates.

Important deadlines can be highlighted, and relationships between activities can be shown, for example by using Excel comment boxes. A broad overview of the project duration is needed as well as a more detailed breakdown of shorter time periods. An example of Gantt chart used in Value+ is available at Section 6.3.

Critical paths are used to identify the timeline for small tasks which support the activities shown in the Gantt chart. For example the Gantt chart might show a workshop or consultation event. The critical path shows the steps that must be taken to make the event happen successfully, such as booking a meeting venue, inviting participants, getting photocopies of handouts to be used. All the tasks are critical; without them the event may not produce the desired results, and thus delay or stop the project. An example of critical path used in Value+ is available at Section 6.3.

Risk logs are used to record possible risks to the project. Risks are scored high, medium, or low depending on their possible impact on the project. Methods which could be used to reduce the risks are also identified. For example, if funding stops the project cannot continue, so this is a high risk. The risk level can be reduced by getting to know the funder's requirements and making sure these requirements are observed, getting reports in on time, involving the funder in appropriate project events, and so on. Legal requirements, such as ethical permissions and health and safety conditions, should be built into the risk log.

A risk log provides an early warning system that shows when things are going wrong. It should be reviewed regularly as risk levels may change suddenly, for example if a worker involved in an essential task falls ill. Priority is given to managing high and medium risks. An example of risk log is available at Section 6.3.

A budget forecast is used to plan how the money will be spent over the project time and shows when funding is expected to arrive. It is related to the time spent, and therefore staff pay, needed for the project activities; the time spent will vary each month. The money must be managed so that there is enough for the activities that will take place towards the end of the project. Contingencies must be built in for unforeseen overspends.

These tools are most effective when all the project partners contribute to the scheduling of project activities, identifying possible risks, and so on. They should then become working documents in constant use, reviewed at least once a month particularly by the lead partner.

Building working relationships between project partners is discussed in Section 5, Working in Partnership.



3.3.3 MANAGING MEETINGS

Communication often takes the form of formal meetings which are planned in advance, have an explicit purpose, and the outcomes of the meeting are recorded. Despite being so common, many people responsible for running meetings have not received training to do so, but have picked up their skills on the job.

This section is about formal meetings. The basic principles can be applied to regular Board meetings, staff meetings, supervision of individual workers or volunteers, conferences, training events, consultation events, telephone or conference calls, video-conferencing, and so on.

During the Value+ research, communication was repeatedly identified by focus group participants as a key issue in patient involvement. Some experienced patient representatives at a Value+ focus group identified attending project meetings with scientists and clinicians as the most difficult part of patient involvement. A further indication that meetings are a problem area in patient involvement are the many guidelines that both patient groups and health authorities have developed on how to involve patients in meetings successfully.

Formal meetings have the same underlying structure. Often, but not always, the meeting topics for discussion are agreed in advance – the agenda, and what happens is recorded – the minutes. One person, the chairperson or chair, takes responsibility for leading or ‘chairing’ the meeting. In small meetings these formal words may not be used, but the description of the roles remains similar.

The chair ensures that decisions are made and the business gets done; this role includes collecting items for the agenda, sending out information to participants in advance, and allocating time to each item at the meeting. The time spent in discussion depends on the chair’s style; some chairs make sure all participants present have an opportunity to understand and discuss the issues in the meeting, others expect that participants have prepared before the meeting and are ready to make quick decisions. Decisions may be made by majority vote or by consensus; finding a consensus means that participants discuss the issues until they reach a position everyone can support. Consensus takes longer, with the benefit that participants usually feel their views have been heard and taken into consideration. The chair then makes sure that the decisions are acted on.

Most formal meetings are recorded in some way, it should be agreed at the beginning of the meeting who should take notes. The minutes taken may record discussions in detail, sometimes there is a short summary of the discussion followed by the decision or action, and sometimes only the actions are recorded. It is helpful to include who has agreed to take the action and when they will do it by! Meeting participants should be given the opportunity to agree that the record summarised at the end of the meeting, or sent to them afterwards, is correct.

None of this is any use, if the person you’re talking with doesn’t feel free to say what they really think.

Value+ focus group participant

Sometimes issues are discussed or decided at meetings that could lead to a legal action, for example, a selection committee’s decision on which candidate to appoint to a job; a disappointed candidate might bring a discrimination case to court if the reasons for their rejection are unclear. Court cases put a big demand on an organisation’s time and money. Board Members can reduce this risk to the organisation by ensuring that they and their staff record any meeting relating to employment, contracts, or any other legal matter, in detail. The record-keeping would include an employee’s supervision meetings with their manager, when the record should be agreed and signed within the meeting, and include reference to any differences of opinion.

With such a focus on legalities and getting business done, it is easy to overlook the human aspects of meetings. Good practice guidelines for involving patients in meetings often highlight these human aspects. For example, when considering accessibility, meeting organisers may provide wheelchair access or hearing loops. Patients may identify many other things which affect accessibility. These may include their previous experience in the building if the meeting is held at a hospital, links with transport timetables, their personal and work commitments, and their physical need for breaks during the meeting, receiving the agenda and background information in time to read it before the meeting, and so on.

No matter how small the meeting, participants need to feel that they have something to contribute and that they are listened to with respect. Face-to-face meetings allow people to exchange views and experiences, to request clarifications and explanations, and to go deeper into interesting aspects of a topic. As a result such meetings may open out new perspectives, and create a stronger basis for working with others. If the atmosphere is encouraging, even the informal time during the breaks are useful. If participants don't feel valued, their input is unlikely to support the purpose of the meeting.

Before the meeting all participants should be informed of the meeting's purpose, any necessary preparation, and how to get items onto the agenda. At the meeting, a good chair ensures that participants are welcomed and introduced, have an opportunity to contribute, and that their contributions are acknowledged. In summarising discussions, the chair can refer directly to individual contributions so that people feel included. Groups which meet regularly sometimes hold special induction sessions to explain everything to new participants, or have a buddy system with an established member responsible for welcoming a new person and putting that person in the picture.

Patient organisations can support patient representatives attending meetings outside the organisation. They can do this by advising the meeting organisers about any special requirements for their patients and making them aware of any relevant patient guidelines. They can provide the representatives themselves with relevant information, an opportunity to talk through agendas beforehand, and a two-way communication channel through their newsletters or website to consult with other patients. They can also provide someone to celebrate success with (or a shoulder to cry on) afterwards!

3.4 COMMUNICATION

3.4.1 INTRODUCTION

In this section we look at the principles of communication, presenting information, and some of the technologies available to support communication. We will discuss issues relating to the cultural differences in Section 5, Working in Partnership.

Research by the Value+ team has clearly identified communication as a key issue in patient involvement. Patients have said they need information about projects in language they can understand. They need to be informed of the results of their involvement, and what has happened as a result of the projects they have taken part in. They have highlighted the importance of personal contact in recruiting patients for involvement activities, and of having a personal contact inside the project to whom they can bring questions or any difficulties. Finding enough resources for translation from one European language to another may also present a difficulty. Value+ has been asked to recommend to the European Commission that more translation support is provided for European health-related projects.

Patient organisations often translate medical information into the level of language that patients understand. They provide guidance for doctors on how to talk to patients about particular conditions, sometimes highlighting everyday issues that doctors may overlook. At a European level, they may make information more available to patients by translating it from other languages. Patient organisations also gather information from patients, so that they can represent the patients' views and needs accurately to policy makers, and can fit their own services to patient needs.

All this work supports communication between different cultures; the cultures of grassroots patients, medical and research specialists, and policy makers. However, Value+ research shows that patients and even experienced patient organisations sometimes find it difficult to work across this cultural divide. Sometimes this is the most difficult aspect of patient involvement.



3.4.2 BASIC PRINCIPLES

Communication involves a minimum of two people, one who sends some type of signal, and one who receives and understands it. The second person may then reply or take some other action as a result of understanding the signal.

If the signal does not arrive, perhaps because the second person is hearing impaired or their postal worker is on strike, then communication has not taken place. If the second person receives the signal but does not understand it, successful communication has not taken place.

There are many levels to consider in preparing a signal. If the levels chosen are not suitable for the people receiving the signal, they are unlikely to understand it accurately. Here are just a few of those levels:

- The language, signs, or symbols; across Europe there are many languages and systems in use and a huge variation in the way individuals use these, perhaps attaching completely different meanings to the same word or symbol
- The information content; the person receiving a message needs enough background knowledge of the topic
- Emotional and cultural aspects; the message reflects the attitude of the person sending the message both to the message topic, and to the person receiving the message. It is easy to misunderstand these aspects, particularly when the message sender and the recipient are from different backgrounds or cultures, or are not in direct personal contact when the communication is received, as with a letter.

All this in just one message, even before the person receiving it considers their response!

Some basic steps can support successful communication:

- Build a rapport, i.e. a positive connection, indicating goodwill
- Find out about the person or people you are communicating with, and their cultures. Don't act on assumptions – check out your ideas
- Use this knowledge to identify the type of language, signs or symbols you believe they will understand
- Organise your information and relate it to what they already know, use examples you believe they will recognise
- Check that your message is tactful and culturally appropriate to the person receiving it
- Give the message, and check out what the other person understands
- For ongoing communication, establish what everyone expects from each other.

Some Techniques for Checking Understanding

Open questions: These are questions that cannot be answered by 'Yes' or 'No' (questions that invite 'Yes' or 'No' are closed questions). "How can this fit in with your work?" will draw out more information than "Do you understand?" or "Is that clear?"

Paraphrasing: Repeat what the person has said to you in different words. If you have misunderstood, they will correct you.

Reflecting: Paraphrase as above, and also name the underlying emotion, E.g. "The train was delayed, you sound really worried that you were a bit late." This invites an answer that may explain the situation a bit more.

Summarising: Make a brief summary of the all issues that have been mentioned. This prompts the other person if they have forgotten anything, and may encourage them to identify the most important aspects.

With phone or face-to-face contact, body language and tone of voice play a part in building a positive connection, and also help provide feedback on how well messages are understood. There is an immediate opportunity to make a check and correct any misunderstandings. Communication that takes place without direct contact at a later stage will build on the goodwill and knowledge gained through this contact.

A group of Belgian psychiatric patients and workers produced a comic strip for children, aimed at reducing stigma.

With indirect contact, the person sending a message knows their communication has arrived or been successful only when s/he receives an appropriate return signal from the second person. It is important to send a response, even if it is not the reply that the sender of the message wants.

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Patient organisations are often involved in two types of advocacy; collective advocacy – working with groups of patients on policy or service delivery issues, or individual advocacy – working with an individual patient on that patient’s treatment and care issues. Advocacy is sometimes described as “ensuring that patient voices are heard”. In fact, advocacy is a process in which advocates also enable the patients with whom they are working to hear the responses to what they are saying, so that a dialogue can begin.

When communication between three individuals or three groups of people is concerned, it is important to lay a positive foundation for future communication. If the participants fall into a “drama triangle” situation, this will delay the resolution of any problems (See [Karpman’s Drama Triangle Model](#)).

3.4.3 PRESENTING YOUR INFORMATION

Why are you presenting information? Who are you presenting it to, and what do you want them to know or to do as a result?

These questions are as important as the information itself, and will help you decide how to get the message across. Should you write a leaflet or newsletter, make an audiotape or a video, put it on your website or send it out by post, give a lecture or put up a poster? All of these methods can be effective if matched to the people you want to reach.

Why? The answer to why may be a broad purpose, for example raising awareness of a particular condition. The desired results may include encouraging people to recognise and seek help for possible symptoms at an earlier stage, reducing stigma, raising funds, or simply getting people to contact your patient organisation.

Broad purposes require a communication strategy with different messages for different purposes. One message may encourage the public to notice and discuss things for the first time, but visible results take time.

Learning requires a number of varied learning opportunities (see [Kolb’s Learning Cycle model](#)), but first people must become aware that there is something they don’t know and be interested in knowing more about. Workers and volunteers should expect any communication strategy to take time and resources, and to plan a follow up on their initial messages.

Who? This question identifies the target groups for your messages. Sometimes messages can be sent in the same form to many different groups, and sometimes the content and form of the message needs to be adjusted for a specific group.

What level of language will your target group find easy to understand? Would people prefer a leaflet or a detailed report? Do they need large print, or more pictures than text? Do they already know a lot about the topic, or do they need detailed background information? Do they use computers? Where would they or their families notice a poster?

A teacher’s tip:

“Tell them what you’re going to tell them.
Tell them.

Then tell them what you’ve just told them”.

When resources are limited, it is important to identify how those resources should be used to reach the desired groups. For example, some patient organisations may prioritise the needs of partially sighted patients, others may be concerned to reach people who speak minority languages. It takes longer and may cost more to get information to patients who do not use email or the Internet.

Effective communication. To be effective, your communication needs to **attract attention** amongst all the other communications that other people are sending out. Your communication needs to be different in some way. For example, a handwritten notice on a board full of printed notices stands out. Unusual artwork attracts attention. The organisation name, contact details and website should stand out on all your communications.

To find out how women in Ireland accessed health information, the [Cancom project](#) interviewed women in their homes, in workplaces, and in shopping centres. As a result, a special health information bus now visits rural villages.



Your communication also needs to **be trusted**. This trust goes back to the relationship you have established with the person you are communicating with, or how your organisation is seen by the public. It is important that everyone in the organisation is aware that their everyday contacts with patients, clinicians and the public affect how the organisation is seen. If you are trying to reach minority communities or marginalised groups, personal contact may be essential in building trust. Find out about their community groups and leaders, and take advice from any organisations who have already built relationships with that community.

Your communication should **be structured** so that your messages are easy to find, and follow a logical order. Complicated information should be broken down into simple steps, with an explanation of any technical terms or acronyms. **Emphasise the key messages** using bullet points, bold type, or your voice, alerting the listener that a key message is about to be delivered. Written information should include instructions on how to get **further information**. If you are presenting information at a meeting, questions can be answered immediately and you can back this up with handouts that people can use afterwards. Egan's Skilled Helper model may be useful for patient organisations which provide information to individual patients.

Maintain interest by including appropriate personal stories, examples, photographs and pictures that support your message. In a patient newsletter there can be a variety of such items. In a meeting presentation, vary your voice, use pauses, and look round the audience so that they feel connected to you. **Practice** your presentation to colleagues, and get colleagues to **check** written communications. Their feedback can lead to simple improvements.

The Plain English Campaign have produced a guide, 'How to write Medical Information in Plain English'. Take a look at www.plainenglish.co.uk/medicalguide.pdf

For guidelines on making a presentation from the Centre for Excellence in Interdisciplinary Mental Health, see Section 6.4.

For anti-stigma campaigns, see Section 3.5.2.

3.4.4 USING TECHNOLOGIES

Information and Communication Technology (ICT) has revolutionised the way we share information. Patient organisations are more likely to share information and documents by emailing each other and viewing each other's websites than they are to send a letter through the post. This may be especially true of international communications.

The Parkinson's Disease Society of Slovenia has produced an anti-stigma video clip, short enough to be attached to an email.

Today patients are getting into contact and forming patient communities and organisations through the Internet. Patient organisations may use text messaging to contact their members. Email campaigns can be used for raising awareness of health issues. If you produce and send by email something that catches the attention of people, they may send it on to their friends.

Health services too make increasing use of ICT. Patients' health records are often kept electronically instead of on paper, and there are proposals for these electronic records to be accessible wherever the patient requests treatment. Treatments too may be supported by interactive technology; one example is the stroke rehabilitation technology trialed by the EC-funded Alladin project. Another is the ICT device for patients with chronic headache being developed by the Comoestas project to monitor overuse of medication. In general the EC is supporting technological developments related both to treatments and to health service delivery.

However ICT is not always a simple solution. Software, or programs, do not work with all operating systems, or may work slowly with old computers. If you have the latest equipment and software, people with older equipment may not be able to open the files you send them.

As this is such a huge topic we can only provide some tips, not detailed information. A good solution may be to have a skilled person in your organisation who can help sort out the problems when they arise. If you haven't got one, borrowing a know-it-all teenager is sometimes better than nothing.

Here is some general information and our tips for using ICT. We do not recommend the use of any particular equipment, services or software. We just draw your attention to some possibilities.

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- A **connection** by wireless or cable is needed to use email or the Internet. The speed with which signals can reach a computer varies according to this connection. A slow connection prevents people, especially in rural areas, from using some websites. The EC aims to make high-speed broadband available everywhere in Europe by the end of 2010, however the work is unlikely to be completed by then.

Meanwhile we suggest you make the home page of your website easy to use. Animations or video clips take longer to download and putting them on the home page may discourage some visitors to your website. When emailing large files such as photographs or presentations, make a smaller version or 'zip' them. The special software needed to create a ZIP file must be purchased, but the software to open them can be downloaded free of charge.

- Guidance is available on website accessibility for people with disabilities. See www.w3.org/WAI/intro/people-use-web
- Some projects exchange documents electronically by using **shared workplaces**. Their documents are stored on a website, and are only available to people who have the right password.
- **Skype** is a free software that can be downloaded from the Internet. It allows calls, video calls, and video conferencing to other computers and also calls to ordinary phones, all within the normal cost of using the Internet connection. **VYKE** is another similar software. For use computer to computer, both parties must have a microphone built in or attached to their computer, and a webcam if they want to make video calls.
- Some companies offer **cheap phone calls within Europe**; a caller dials the company number first, then the foreign number they want. The caller pays less than if they dial direct. However usually there is a connection charge as well so their service may not be as cheap as it appears at first. Use the Internet to check current offers.
- Most software frequently used for office work, such as word processing or spreadsheets, have a 'track changes' and 'add comments' option. This is useful if you want other people to comment on a document you have sent to them.
- **Microsoft PowerPoint** is widely used for presentations, and has the advantage that the presentation can be easily emailed or carried on a memory stick to the meeting. Photographs and simple charts can all be put onto a PowerPoint slide. If you use a video clip, check whether the equipment available at your meeting will play the sound synchronised with the picture.

Audiences can read short bullet points more easily than long texts. The best colour scheme for the partially sighted is white text on a blue background.

- **Digital cameras** are useful for publicity photographs and short video interviews. Make sure you have permission to photograph people and to use the photographs for publicity. Stigma is an important issue for many patients, it is unacceptable to take a photo of them and use it without their agreement.

Some patient organisations and other patient support services provide computer time and support for grassroots patients wanting to find information on the Internet. It is important to remember that some grassroots patients still prefer to use the postal service or the telephone.

The Dam Society of Slovenia has built and maintained the first website offering support for depression in the Slovenian language: (www.nebojse.si). The Dam Society has achieved this with little funding and no professional support. Everyone in the Society is a volunteer.

3.5 MANAGING PATIENTS AS VOLUNTEERS

This section is about individual patients who take on roles in projects because of their knowledge and expertise as a patient. They may become involved through clinical care teams or a patient organisation, or another project partner, not itself a patient organisation, which supports patient issues. The involvement itself may be formal, planned into the project from the beginning, or an informal development during the project.

Value+ recommends external mentoring for individual patient/patient representative volunteers who are involved directly in projects, without the support of a patient organisation behind them.

Throughout the European Union, there are few recognised guidelines for involving individual patients in this way. The clinical and ethical guidelines that health workers must follow when recruiting patients as research subjects, perhaps to test a new treatment or technique, do not apply to the situation where patients are colleagues rather than research subjects.



This section provides guidance on the recruitment and management of individual patients involved in projects or indeed other involvement activities. It describes why patients get involved, what might discourage them, and what supports them.

The status of involved patients and their representatives may be as:

- Unpaid volunteers
- Paid for specific, limited, tasks
- Employed within the project.

When patients or patient representatives are employed within a project, they are protected by employment law. They will have an employment contract that sets out their responsibilities and those of the employer. They may have a manager, and regular contact with colleagues in the project team. Support is available if there are problems.

Patients and their representatives who volunteer, or who are paid a small amount for a specific limited task, for example, attending a meeting, are not part of the formal employment structure and may not access support in the same way. Their rights and responsibilities are less clear. Though they bring great motivation to the tasks, their involvement has to come second to managing their condition or caring responsibilities, and paid employment. They may have to overcome many practical difficulties to be involved at all. Because they put such effort into their involvement, they want to feel their time has been used well.

There is a need to ensure that patient involvement is a positive experience for all concerned. Projects, patient organisations, and any other organisations involving patients, need to create a supportive structure for patient involvement. This structure should support patients to fit involvement into their lives. We discuss this more in Section 3.5.4.

3.5.1 WHY DO PATIENTS WANT TO BE INVOLVED?

Understanding why people volunteer is essential to recruiting volunteers, and to retaining them in the organisation.

Volunteers are motivated in several ways. These are just some of them:

- Wanting to contribute to their community and work towards positive change
- Having a meaningful occupation
- Getting to know new people
- Exploring a possible career change, or building their skills with a view to future employment
- Being committed to a cause – personal or family reasons may influence the choice of cause
- Because the time they can give is limited, they are motivated by the impact they can see from their efforts, and the value others place on their work.

All these things can apply to patients and patient representatives, but there are additional strong motivators specific to patients that include opportunities to:

- Support the development and accessibility of new treatments, which could have a direct impact on their own lives
- Meet others with similar conditions, to compare experiences and learn from them
- Build something positive from their own difficulties; this can have a positive psychological impact on their wellbeing.

Respect for volunteering may be linked to the [apprenticeship](#) or [internship](#) tradition. The opportunity to learn new skills from a recognised expert raises the status of working without pay. However in some communities, unpaid work may be linked with exploitation. It may be difficult to recruit volunteers from these communities, unless a link can be made with activities that are respected and have high status.

In some countries guidance on good practice with volunteers is available, and this guidance can also be applied to patients who become involved as volunteers. For example, the Volunteering England website www.volunteering.org.uk/ has a Good Practice Bank, and the Volunteering Ireland website www.volunteeringireland.com/ has a Charter for Effective Volunteering.

The European Volunteer Centre (CEV) website www.cev.be has a list of members in different countries.

3.5.2 ANTI-STIGMA CAMPAIGNS

Stigma is the shame and disgrace attached to something which is regarded as socially unacceptable, and it leads to discrimination. Public ignorance and prejudice about some medical conditions can result in patients avoiding day-to-day activities which could improve their physical health and their quality of life, because they fear stigma. Stigma also affects employment, making it harder to get or retain a job. Prejudice has a negative effect on psychological wellbeing. Those who experience discrimination are unable to play a full and equal part in their community.

The Lithuanian Multiple Sclerosis Union holds an annual duck race. This raises public awareness and acceptance of multiple sclerosis, as well as bringing in funds.

For a patient, involvement may mean taking a public role associated with a condition which might otherwise not be obvious to everyone. They may therefore experience stigma which they could otherwise avoid. It is clear that stigma is a significant barrier to recruiting patients for involvement activities.

Stigma has been identified as an issue at several Value+ events. In one Value+ focus group, four out of ten participants identified stigma as an issue for the conditions they represented. They also expressed concern about rising discrimination in health provision that can affect smokers, overweight patients, people who self harm, or use drugs or excessive alcohol. Indeed any groups about whom assumptions are made without the causes of their behaviour being examined can experience stigma and discrimination. We include this section on anti-stigma campaigns at the suggestion of that focus group.

The LISS (Lithuanian Multiple Sclerosis Union) Challenging MS project, and the Mental Health Europe project – Good Practices in Combating Social Exclusion, were directly aimed at reducing stigma and discrimination. Their strategies for combating stigma included public education to reduce the ignorance that lies behind prejudice, the education of specific groups, the provision of information on legal rights to patients, and working directly with employers.

See www.mentalhealth-socialinclusion.org/assets/files/Good Practices Publication_Final.pdf for the final report of the Mental Health Europe project.

Awareness campaigns, so that the majority of the population knows some basic facts about a particular health condition, were seen as essential. Easy-to-understand information on leaflets and posters is made available in public places, not only in medical settings. This information signposts the patient organisation and its website, where more detailed information is available. Tactics included getting famous people with the condition involved with the patient organisation, by inviting them to important events, getting them to act as spokespeople, or take part in information films. This challenges stereotypes and provides patients with positive role models. Personal stories also attract interest – telling it how it really is.

Belgian psychiatric patients sell home-made food at the annual Ghent open-air jazz festival.

Patient organisations can increase the coverage of awareness campaigns by organising or taking part in local and regional events. This brings patients together with their communities in a positive context. Such events raise awareness of the condition, combat stigma, help to raise funds, provide opportunities to recruit patients and supporters, possibly also offer opportunities to network with and lobby politicians and healthcare providers. If the events take place regularly, they – and the condition they are connected with – become part of the life of the community.

It is important to attract media attention to positive stories, and to concentrate on facts. Information articles can be targeted to particular publications, for example, women's magazines. In some countries, radio is more likely to be targeted by patient organisations for spreading information, as television is felt to be more interested in sensational 'bad news' stories which increase stigma.

The national charity MIND in the UK now provides consultancy and training for employers about managing mental health issues in the workplace, to reduce discrimination there.

www.mind.org.uk/About+Mind/Mind+Workplace/

Legal challenges to discrimination are only possible if backed by national law. The current UK 'Time to Change' campaign www.time-to-change.org.uk/ includes funding to bring cases where the UK Disability Discrimination Act may have been breached.



3.5.3 HOW AND WHERE TO RECRUIT

Volunteers can work at any level in an organisation; Board Members who take on legal responsibilities for the governance of the organisation may be volunteers. Both patients and their relatives may consider volunteering in a patient organisation. In this section we talk about 'potential volunteer' during the recruitment process, and 'volunteer' once the person has been recruited. These terms refer both to patients and their relatives, and the same information is relevant to any other person who might wish to volunteer with the patient organisation. When we refer to 'patients' we mean only patients, not their relatives.

'Patient involvement' refers to the involvement of patients or their representatives on matters relating to patients. The representatives may be workers or volunteers from a patient organisation. These workers or volunteers may themselves be patients or relatives of patients. For good practice in representing patients, see Section 2.4.1. For good practice with the gender dimension, see Section 2.5.3. Patients' relatives may also become involved on matters relating to carers. This is called 'carer involvement'. We do not discuss it in this toolkit, except to highlight that while patient and carer interests are often the same, it is sometimes important to recognise there is a difference.

Recruiting volunteers and recruiting paid staff require the same steps, although they may not be carried through with the same formality and detail with volunteers for all tasks.

A **job description** is drawn up describing the task, and a **person specification** describes the knowledge, skills, experience and attitudes required to carry out the task. These, and details of the **conditions** – hours, pay, other rewards – and the **organisation** and the **project** are sent to people who reply to an **advertisement**. Anyone who is interested signals their interest with an **application form**. Further information exchange and negotiation then takes place, often at an **interview** or **discussion**, when each party decides whether they want to work with the other. If they do, a **contract** is signed, or in the case of volunteers, there may be an **agreement**.

When recruiting volunteers, a balance must be found in the recruiting process; if it is too formal, potential volunteers may be discouraged, feeling the task is beyond them. If it is too informal, volunteers may take up the task with expectations which cannot be met, leading to dissatisfaction for everybody. Informality can give the message that the task is not really valued.

It is often better to introduce face-to-face some of the information that must be exchanged. It is then possible to establish a rapport and explain why some procedures are required. The procedures may be related to funders' or insurers' requirements, national law, or the organisation's own policies. Any information given verbally should be backed up by written information.

Value+ has received a strong message from patients and patient representatives that patient involvement is most effective when it is planned in from the beginning. Paying attention to the individual patients and patient representatives who will carry out the involvement tasks is part of that planning. Finding out what might motivate patients or their relatives to volunteer, and what might discourage them, provides important information that can be built into your planning.

We now look at the recruitment stages in more detail:

- **Job description** This should describe the task accurately. For example, it should make clear whether a volunteer who attends a meeting regularly should be in regular contact with grassroots patients to discuss the agenda items, or give views from his or her own experience. It should be clear whether someone volunteering in the office is expected to answer the telephone information helpline.

It is not possible to foresee all the tasks that will arise during a long project. Existing volunteers and previously involved volunteers may be offered additional tasks, but they should not feel pressured to accept them.

For volunteers who carry out a regular skilled task, the job description is detailed. For brief tasks the job description may be merged with other topics on a short information sheet.

See Section 6.4 for a detailed job description from an NGO.

- **Person specification** Equal opportunities recruiting has arisen from anti-discrimination laws. To protect themselves from anti-discrimination cases, employers are careful to exactly describe the qualities of the person needed exactly; the person specification must relate to the tasks in the job description. Employers then measure applications and interviewees against this specification. Although a legal case could not be brought when the work is unpaid, it is important for patient organisations to be seen to select volunteers fairly, especially when training or other benefits are included.

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Sometimes when funders or policy makers require patient involvement, little time is put into recruitment. The result may be that patients or patient representatives who become involved have little knowledge of the stage of illness or the services under discussion, and cannot make an informed contribution. This poor practice encourages resistance to patient involvement. Patient organisations can promote good practice by using an accurate description in the person specification.

- **Conditions** These include the expected time required, where and when the task is expected to be carried out, any support or equipment that will be provided, training that must be completed, what expenses can be claimed, and any rewards.

Although many patients and patient representatives give their time freely, it should not be expected that they do so. If a substantial time requirement is needed for a task, it should be budgeted in as paid work.

Time for recruitment, support, and training should also be included in the budget. There is a high time cost to involving volunteers.

- **Organisation and project details** The organisation details are probably available in a patient-friendly format. The project details need to be described in simple language. It is important for patients and other volunteers to see how their work will contribute to the overall outcomes of the project.
- **Advertisement** An advertisement should be attractive, carefully worded, and sent out through the patient organisation's usual communication channels. If the patient organisation has been involved in planning the project and applying for funding, grassroots patients and other potential volunteers may already know about the project and have expressed an interest. When the patient organisation is ready to recruit, they should contact these people directly.
- **Application** When someone volunteers with your organisation, you need to know personal information such as contact details which are usually collected on an application form. The amount of information will depend on the type of work; you should not collect personal information that you do not need. In addition, some patient organisations require references for volunteers, and a criminal record check is required in some countries if the volunteer will work with children or vulnerable adults.

Most potential volunteers would find it unreasonable to fill in an application form before they have had an opportunity to discuss the involvement opportunity with someone from the patient organisation.

The application form can be given at the interview or discussion, and returned by the person if they are interested in taking up the involvement opportunity.

- **Discussion** This is an opportunity for the patient organisation and the potential volunteer to discover whether the involvement opportunity will suit the volunteer. The organisation should describe the involvement opportunity, the training required, and the support offered. It should also find out what an individual wants to gain from the involvement opportunity, and inform the person whether their expectations can or cannot be met. The organisation should also inform the person if he or she is not suitable for some reason; it should not be afraid to say no – it is protecting the interests of the patients it represents, and those who will benefit if the work is done well. The organisation may identify other involvement opportunities for which the person may be better suited.

Information about patient and patient representative motivations and limitations (such as time availability, mobility issues, knowledge or skill gaps) collected from these discussions enables an organisation to adapt their conditions to provide a more supportive environment for patient involvement.

It is important during the discussion to create an open and encouraging atmosphere so that the potential volunteer feels free to talk and ask questions. For example, the person may need to know that the patient organisation will keep their personal details confidential. The worker may have to encourage less confident individuals to recognise their own skills. The reason for any information requested from the potential volunteer should be explained.

Patients and their relatives may need to 'tell their story' before they can concentrate on anything else – whether that is an involvement task, or simply a contact with a patient organisation for information. They need to have come to terms with the diagnosis before they are ready to even consider being involved. They must be able to put their own issues aside enough to concentrate on the task, rather than using the task to solve their own problems.



- **Agreement** Volunteers usually receive an introduction to the organisation so that they understand the organisation's policies and procedures (work methods). They may sign an agreement that they will apply these policies and procedures in their work for the organisation. Some funders require that all workers and volunteers in the organisations they fund have signed such an agreement.

The agreement also includes things the organisation will do, for example pay expenses or provide training.

In practice, if a volunteer breaks an agreement, all the patient organisation can do is ask the person to stop volunteering and perhaps to leave the organisation. If the volunteer values the things which his/her work with the organisation can bring, for example, respect for skills and status or social contact with other volunteers, it is a strong reason to keep to the agreement.

Clinicians sometimes say they are concerned that involved patients or their relatives have not been trained in confidentiality issues, and do not have to answer to anyone if they disregard confidentiality. Patient organisations know confidentiality is essential to patient trust. They do have confidentiality policies and train their staff and volunteers; it is a small step for volunteers to sign an agreement to show they are aware of confidentiality issues and have received training in them.

We now move on to where to recruit volunteers. Finding patients or relatives willing and able to be involved is time-consuming and difficult. Organisations for rare diseases face particular problems, owing to the small number of patients with such conditions.

For an organisation, the work of recruiting patients and patient representatives for involvement begins long before a patient or their family members are ready to consider involvement. Patients, and in turn their families, often feel isolated when they receive a diagnosis for a condition they know nothing about. The isolation reduces when they find that there are organisations, perhaps even local self-help groups, for patients with the same condition. Their impression of the patient organisation begins at this point.

There are many ways to reach out to patients and their families; patient organisations set up websites, provide leaflets available in public places, doctors' surgeries and clinics, develop links with specialist nurses and doctors who pass on their information to newly-diagnosed patients, hold awareness events, get articles into newspapers and health magazines, they may even get health messages included in packaging for everyday items. They may also support self-help groups or provide services directly to patients in health or care settings.

All these communication channels build up a picture of the patient organisation; all of them can be used to raise awareness of patient involvement opportunities.

When patients or their relatives do contact your patient organisation, whatever the reason, this is an opportunity to recruit members, develop mailing lists for printed or electronic newsletters, or invite people to join a database. It is important not to waste these valuable opportunities, and the first person-to-person contact with someone in the patient organisation must make a good impression. Workers or volunteers who meet patients and their relatives or answer telephones must have adequate training, and respond sensitively to people in distress.

Once someone has joined your mailing list, your organisation can keep them interested by sending out newsletters about your activities, including patient involvement inside the organisation and involvement activities outside the organisation. Only a minority of patients or carers actually take the step of becoming involved. However the more patients and their families know about patient involvement, the more they understand what patients, or carers, working together could achieve in relation to their own condition, and how they themselves could take part. Personal stories in a newsletter or on the website can inspire others to be involved.

Finding patients or patient representatives for specific involvement opportunities may require a recruitment drive to back up the advertisement. Workers and volunteers could visit community, health and care settings to talk about their organisation and its activities. Staff in specialist clinics could be approached, and asked to mention the involvement opportunity to patients or relatives. Personal contact is important, with an explanation of what the individual can bring to the task; men especially are more likely to respond to a personal approach rather than to a poster.

Patients or relatives may contact your patient organisation to enquire about involvement opportunities, whether as a general enquiry or in response to an advertisement or recruitment campaign. It is essential that they receive a quick reply and are kept informed, for example about when the involvement activities are likely to start. It is useful to have an administration system to record any contacts with prospective volunteers. This allows your organisation to check whether information has been sent out, and do other appropriate follow-up. The Value+ Involvement Opportunity Checklist can be used with each prospective volunteer to ensure that all the necessary information has been covered with him or her, either in writing or during an interview or discussion. Like all our tools, organisations can adapt it to their own requirements.

Public and Patient Involvement policy (PPI) in England requires patients to be involved in public health services. Databases have been developed in some areas for patients interested in involvement. The patients give some information about their condition, and the ways in which they are willing to be involved, for example, by responding to questionnaires sent to their home, taking part in recruiting doctors and nurses, attending meetings. Details of involvement opportunities are sent out only to those patients identified through the database as being interested and having relevant experience. Some opportunities are only open to patients who have completed training. Patients must receive a small payment for involvement activities, but not for attending training.

For the Value+ Involvement Opportunity Checklist, see Section 6.3

As interest in patient involvement increases, patient organisations are approached more and more often to find or advertise for patients to take part in projects in which the patient organisation itself is not directly involved. Patient organisations decide whether the request should be passed on to grassroots patients using criteria developed with those patients, for example the source of funding.

For Asthma UK's 'Checklist for researchers wishing to recruit participants to their research opportunities through Asthma UK', see Section 6.4.

3.5.4 THE WORKING AGREEMENT

After all this preparation, you've eventually found a patient or patient representative who wants to volunteer for the task. The last thing you want to do is lose him or her! Luckily, as you prepared the recruitment process so well, you both now understand what the task is, and what to expect from each other. If the volunteers have completed an introduction to your policies, they know what to do if they have a problem. So all you have to do is provide the support you promised.

The Value+ research has repeatedly identified the importance of personal contact in patient involvement. Patients have requested that projects should have a contact person for the patients they involve, and that patients should receive feedback on their work as well as support. They are volunteering partly because they can see that it is in patients' interests for the task to be done by a patient. As patients themselves they have an interest in the task being done well. Patients new to involvement very much want to know whether and how they could do their task better. This feedback is important to them. The same applies to patient representatives who become involved.

We suggest that a volunteering patient or patient representative should have a contact person inside the patient organisation, and schedule regular meetings with that person. Volunteers may benefit from group support or training sessions, but this should not replace their one-to-one time with their contact person.

Support with the contact person can take several forms, as appropriate and required:

- Discussing and providing feedback or quality checks on recently completed tasks
- Planning and preparing future tasks
- Supporting with the emotional aspects of working with patients, or representing patients
- Identification of the volunteer's training and coaching needs
- Updating the volunteer on relevant developments in legislation, policy, and funding, and developments within the patient organisation
- Ensuring that the work continues to fit with the volunteer's health and personal commitments
- Ensuring the volunteer completes their expenses forms on time.

Some aspects of support are so important that they cannot be presented in bullet points. Here we focus on training, handovers, and thanking volunteers.

Training

No matter how skilled the volunteer, if they are new to working with a patient organisation they will need an introduction to its policies and working methods. Other training may also be required, depending on the volunteer's skills and how specialised the tasks are. As motivated volunteers gain confidence, they may wish to take on tasks which they were originally unwilling to try, such as representing the patient organisation at external meetings. They may request additional training or coaching at this point.



The European Commission is proposing that 2011 should be a European Year of Volunteering, with events to share good practices and highlight the benefits of volunteering.

It is difficult to find training courses that are appropriate for patient involvement needs; patient organisations are learning themselves as they struggle to be included in health-related projects. Often organisations do not have enough volunteers for a learning group, even if they develop their own training. Individual coaching within the patient organisation is one answer; sharing training delivery with other patient organisations could be another. Very little or no training is currently provided by health authorities.

Patient organisations have to manage their time and money resources carefully, and concentrate on their aims and strategies. They must make hard decisions about how much training they can provide for volunteers who take up involvement opportunities.

Handovers

A good handover means ensuring that the contact person knows enough about the volunteer's work to continue the most important aspects if the volunteer is unexpectedly absent. Understanding the importance of their work for other patients, volunteer patients may put themselves under too much pressure to continue volunteering when they are unwell and really need to rest. Their own health is a sensitive issue that patients should really judge for themselves; however the quality of their work at such time affects the organisation. Taking a break when unwell could be recognised as good practice for workers and volunteers inside the patient organisation. The decision to take a break is easier if the volunteer knows someone else in the organisation can be adequately briefed, so the work can be continued in their absence.

It is discouraging for a volunteer to return from a short sickness to find that months of preparation work on an important issue have been lost, because no-one else knew enough to attend a meeting, or meet some other deadline, in the volunteer's place. The volunteer may believe that no-one else thought the work was important, and lose their motivation to continue.

Thanking your volunteers

The care you have put into recruiting volunteers and supporting their work should tell them how important that work is to you. However, it does help to say it out loud and in writing as well, if your organisation publishes something to which volunteers have contributed.

We have received strong messages during the Value+ research about the importance of informing involved patients and patient representatives about what has happened as a result of their work. When the involvement activity is part of a project, the impact on health policy or treatments may not be known until a long time after the project has closed. In this case, your patient organisation and the other project partners should agree on a method of collecting and sharing such information, so that it can be passed on to the patients and patient representatives who were involved.

Thanks are not always enough: some patients see volunteering, perhaps with a patient organisation or other supportive organisation, as a way to practise their skills before re-entering employment. They may want written confirmation of the training they have completed, or request a reference for the work they have done with the organisation, sometimes a long time later, when their contact person has also left the organisation.

Of course, an organisation has no obligation to give a reference, and should never give a misleading reference, but it is a shame if it refuses to give a reference simply because it does not have any record of the volunteer's work or training.

Some organisations keep a record of the support sessions with the contact person; the volunteer agrees on the record at the end of the session and keeps a copy. If the volunteer leaves, the organisation summarises the volunteer's experience and training, and agrees it with them in the same way. Then if the volunteer requests a reference a long time later, the information is still available. An alternative might be to give a certificate summarising the volunteer's experience and training with the organisation when he or she leaves.

European Projects





4.1 CHAPTER OVERVIEW

This chapter gives a general description of the process of applying for funding from the European Commission. It highlights what a patient organisation should consider when putting together a funding proposal, and points to remember during the project, if the proposal has been successful.

Each EC funding programme, and the calls within those programmes, have requirements that must be met by the partners who come together to prepare the proposal. These requirements must be checked very carefully, as they are different for each funding programme and funding call.

4.2 THE EUROPEAN COMMISSION AND ITS FUNDING

The European Commission has several Directorates-General, responsible for specific policy areas. Each Directorate-General (DG) is led by a Commissioner appointed by the Member States, with the European Parliament's approval. Each DG announces its policies, and funding programmes to make those policies a reality. The general purpose of all EC funding is to build the European community.

Each funding programme, which will last for several years, is introduced by an announcement which is a broad and general description of the programme. This announcement is followed by a series of funding calls which describe in much more detail what the funding can be used for and who can apply. Calls are open to organisations which can show that the activity they want to carry out fits with the policy and the details in the funding call. For example, training provided for patients to help them get back to work might fit with the employment policy, or with a specific funding call aimed at supporting disadvantaged people to get into work. Each funding call has a tight deadline, often two-three months from the date of the call; organisations must put in their proposals before this deadline.

An introduction to European Union funding can be found on the Europa website http://ec.europa.eu/grants/introduction_en.htm.

You can search for funding available for the activities your organisation wants to carry out from the grants index page http://ec.europa.eu/grants/index_en.htm.

A short summary of some funding programmes and other European news may be found on your country's webpage from the 'Commission representations' link on the Europa webpage http://europa.eu/euinyourcountry/index_en.htm.

The Directorates-General can be found using the 'Who's Who' link on the European Commission homepage. The Directorates that run programmes which may be most relevant for patient organisations are:

- DG Education and Culture (DG EAC)
- DG Employment, Social Affairs, and Equal Opportunities (DG EMPL)
- DG Enlargement (DG ELARG) – for countries preparing to join the European Union only
- DG Enterprise (DG ENT) for issues like the pharmaceutical policy
- DG Environment (DG ENV) – may award grants to NGOs which work with environmental issues
- DG Health and Consumers (DG SANCO) – the Public Health Programme
- DG Information Society and Media (DG INFSO) – funds project which develop electronic and technological software, devices, and equipment
- DG Justice, Freedom, and Security (DG JLS)
- DG Regional Policy (DG REGIO) – includes the European Regional Development Fund
- DG Research (DG RTD) – includes the 7th Framework Programme.

Clearly it takes time to research suitable funding. Currently, there is no quick solution to finding out information about EC funding calls.

Patient organisations operating at a European level may notify their members of new calls. Large corporations, research institutions, and so on employ workers to watch out for funding opportunities; they find out when EC funding calls will be announced so that they can be prepared in advance if they are eligible to proposal. They do this by watching the Directorate-General websites and announcements in the newspaper *European Voice* – www.europeanvoice.com/. Patient organisations may be able to link up with such organisations and get on their email lists.

The open health forum organised by DG SANCO every three years is a good place to find out what the topics of calls in the health field are likely to be. The larger European health-related conferences for example, European Health Forum Gastein and the European Public Health Association conference can also be good forums for understanding topical, upcoming challenges.

The European Citizens Action Service (ECAS) www.ecas.org/ aims to empower citizens and civil society inside the European Union, and runs an advice service for its members. Every year ECAS publishes a European Union funding guide for NGOs.

When new funding programmes are launched, some programmes hold an information day for prospective applicants; this provides guidance on the content of the call and the administration required for projects funded by the programme. There is no support or training available from the EC to complete the funding proposal itself.

Some Directorate-Generals have a list of national contact people for each EU Member State. We include the website links to lists for some DGs and funding programmes in Section 6.5. If you have difficulty finding the right person, contact the DG through the Europa website, or ask your Member of the European Parliament (MEP).

4.3 WHAT IS AN EC PROJECT LIKE?

EC-funded projects are about building the future of Europe. Generally they require partners in at least three European countries, and it must be possible to apply the project results in more than one country.

Patient organisations will find themselves working with partners in other countries. Some patient organisations, for example larger organisations, those for rare diseases, and umbrella organisations, may be used to looking outside their own countries to find or share expertise. They have experience of having work contacts with people in other countries, though some of the workers, members, and grassroots patients in the organisations may not share that experience. In practice, having work contacts with people in other countries may fall to those in the organisation who have appropriate language skills.

Working in a European project means that people in the project communicate with their partners by phone or email, and may rarely meet face-to-face. Face-to-face meetings may mean long journeys, staying away overnight, and a heavy workload to get through, in order to make the most of the valuable time together.

The reward is that the patient organisations achieve much more than they could by working only within their own country. The results of that work reach more patients, and greater pressure can be brought collectively to achieve changes in health policy. Some benefits will go beyond the project itself; the relationships and links established during the project may continue to support the patient organisation's work well into the future.

Putting together a funding proposal requires a lot of effort, and only a small proportion of funding proposals are successful. We describe the proposal process in detail in Section 4.7.

If the proposal is successful, the Directorate-General providing the funding allocates a project officer to work with the project. This officer may be referred to as a scientific officer or a policy officer depending on the project topic and their Directorate-General. The project partner identified as the lead partner in the funding proposal will appoint a project co-ordinator who is the contact person for the project officer. If any partners have questions for the project officer, they must go through their project co-ordinator. In large projects there is sometimes a scientific co-ordinator for the research side, and a project manager who takes care of the administration. The appointment of the project co-ordinator is key to the success of the project; it is essential the person has sound project management experience.

During the negotiation process for the funding, a timetable is agreed between the project and the EC. This shows when the project co-ordinator must submit reports, the dates by which specific project activities must be completed, and the intervals at which the funding will be paid.

Although only the project co-ordinator reports to the project officer, all project partners are responsible for ensuring that they keep to their budget, that staff timesheets are completed, that there are receipts for everything on the expense claims, and that they provide any other information required for the report. There may be some adjustments to budgets as the project progresses, for example if one budget area does not spend as much, or more than anticipated.

The next funding payment can be delayed if a report is not sent to the project officer at the right time. If the agreed project activities have not been completed, or not completed in a satisfactory way, some money may be held back until this is put right. If one part of the project cannot be completed, none of the money budgeted for that activity will be paid.

The final funding payment is made after the final project report has been accepted; this will be some months after the end of the project because of the administration time required. The time will be longer if the project officer requests changes or more information after the final report is first submitted.



4.4 SKILLS AND CAPACITY FOR AN EC PROJECT

Here is a general description of the skills and capacities needed in a patient organisation, both to put in a proposal and then to take part in a project. These are in addition to the skills and work time needed for carrying out the project activities.

The Proposal:

- The **time** required to put in a good funding proposal should not be underestimated. To research where you might get funding for your activities, the criteria you have to meet, to find partners and prepare a proposal with them, will be a long process. You also should not count on being successful. Only a small proportion of funding applications to the EC receives funding. Even when a proposal is accepted for negotiation, the EC may impose conditions which the project has to meet, cut back the activities the project wishes to carry out, or cut down the time allowed and the money it is prepared to give.

There is no EC funding for the time spent preparing the proposal. It cannot be taken out of any money awarded to the project.

- Good **research skills** and **document skills** are required – in other words, finding the right information and reading all the instructions. Your project proposal must relate your proposed activities to a suitable and available funding stream, and the relevant EC policies. Someone in the project consortium must read the guidance carefully – not an easy task, because the EC has developed its own jargon. Once the guidance is understood, the people working on the proposal must then ensure that it includes all the information required.
- **Communication and liaison skills** are required within your own organisation, and to work with partners. You need to find out what the project calls for, and fit your proposal to those requirements. You also need to get to know your partners, and find out how to communicate with them effectively. The first task here is ensuring that all the partners understand and agree to their proposed tasks as described in the project proposal.

Many patient organisations act as a communication channel between grassroots patients and health professionals, and they may take this liaison role within projects. This often includes the translation of technical jargon into patient-friendly information in a friendly format.

- **Planning skills are necessary** – all the project activities must be carefully costed and included in the proposal; they cannot be added afterwards. Value+ planned travel and subsistence costs for patients to attend focus groups – but forgot that the facilitators would need to travel to distant venues too!
- **Additional funding** may be required, as the EC often provides partial funding and usually expects project partners to contribute some co-funding.
- **Presentation skills** – the patient organisation may take part with other prospective partners in various presentations to the funding committee as part of the negotiations. The patient organisation may also be involved in presentations about the project results, sometimes on a yearly basis. Grassroots patients' voices can strengthen these presentations. This is an area where patient volunteers may appreciate receiving training.
- **Technology and equipment** like email, Internet, and other forms of electronic communication are essential for contacting project partners quickly and cheaply, and sharing documents with them, even if they are in the same country. This will be necessary both while the proposal is being prepared, and during the project if the proposal is successful.

There may be other equipment or software which is essential for your project, particularly for producing information in patient-friendly formats.

Several patient organisations have asked Value+ to recommend that the administration for EC projects should be made simpler.

Running the Project:

- **Management and supervision** are required for the staff and volunteers working on the project. You will need to provide a work introduction for anyone new taken on to work on the project, and existing staff and volunteers may need extra training for any new tasks.
- **Language skills** are useful because working with partners in other countries will bring up language and translation requirements. In many EC projects, English becomes the main language of communication. Electronic translation packs can be added into the budget.

“Patient representatives and also possibly individual patients are likely to be your project champions, e.g. interviewed in the media, and maybe even to mediate if the research is criticised by others. They may need interview and presentation skills and confidence to do this”.

Patient representative from EC project

- **Good book-keeping and financial management** are crucial. The accounts, timesheets, etc. must be submitted in the format and on the forms required by the EC. You should keep your filing archives for five years following the end of the project, because the EC can ask to check your books at any time until then.
- **Recording and reporting skills** for keeping information throughout the project. Project recording should be designed with the requirements of the final funders report in mind, and also the requirements of any publications designed for patients, the public, or other stakeholders.
- **Lobbying skills** for when the project is finishing, the project partners may wish to lobby on the outcome of their project. This might be to continue or expand a service developed by a project, or to achieve changes in policy. The projects should ensure that the relevant decision makers have heard about their recommendations. This requires research to identify who the relevant decision makers are, and what current development areas are. The partners can then take advantage of any significant opportunities to attract the decision makers' attention to their recommendations. You can build on the information you gathered when you prepared the project proposal, but more often you are building on the information you uncovered during your project.

If your organisation cannot meet all these requirements, it may still be possible to take part in a project if other project partners provide the expertise that you lack. The Value+ checklist may help patient organisations to identify where they need additional training, or support from potential partners, to consider becoming a partner in a project.

See Section 6.3 for the Value+ Skills and Capacity Checklist.

4.5 FINDING AN IDEA

The idea for your project will be strongest if it ties in with the strategy for your organisation. The strategy itself will be strongest if it is developed out of the views of your members, and grassroots patients. What do your members want your organisation to do with or for your patients? What information have you gathered from your everyday activities to show the project idea benefits your members in some way? It will strengthen your funding proposal if you add this information; it could be, for example, an analysis of the issues raised by people ringing in to your helpline.

Your organisation then needs to consider what can be added to the project by working with other organisations in other countries. To gain funding from the EC, the idea for your project must contribute in some way to building the European community, be tied in to the policy and priorities behind the funding programme, and the details of the particular call.

The EC is spending money that comes from the citizens of Europe, and requires much more evidence of how the money has been spent than some other funders; for example, the EC requires timesheets for each person working on the project.

Your organisation must find and work with a partner organisation which wants to do something similar. Depending on your project idea, you may also want a partner or partners with other expertise, for example a research organisation. Working with organisations in other countries can make communication between partners more complicated.

To make this extra work worthwhile, your organisation needs to be sure of the advantages of a European project. Will the European aspect of the project idea add enough value to the work you want to do to justify the extra work connected with EC funding? Is the EC the best place to find funding for what your organisation wants to do? Putting together a funding proposal requires a big time investment, so it is important to target the right funder.



4.5.1 SHOULD WE GO AHEAD?

At some point your organisation should weigh up whether and how to continue. You may be trying to build a consortium around your own idea, or have received an invitation to join with another organisation in a project that they will lead. You need to consider what skills and competencies the partner organisations will bring to the project, and whether they will be reliable partners. Value+ has developed a tool which may help organisations make this decision. It can also help organisations identify what they want to gain by being involved in the project, so that they can set their own performance indicators to evaluate the project.

See Section 6.3 for the Value+ tool 'Is this the right project for our organisation'?

4.6 BUILDING A CONSORTIUM

A group of organisations which join together in an EC project is known as a consortium. The type of organisations needed in the consortium depends on what the project wants to achieve. For example, the patient organisations which formed the Value+ consortium felt the project was more likely to be funded if an organisation with an established research reputation was invited to join. They therefore invited such an organisation to join the consortium.

Once again, the Value+ Skills and Capacity Checklist can be used to identify how the partners between them can pool their experience to achieve what they want to do. One organisation will take the lead, perhaps the one with the most capacity or experience rather than the one with the original idea.

See Section 6.3 for the Value+ Skills and Capacity Checklist.

To attract partners, a good description of the project idea is essential. The description can be sent to any organisation which might be interested, starting with the organisations who already network or link with the organisation. Their comments will be useful in finding partners and developing the project idea, even if they do not wish to join the project. The prospective partners should meet together if at all possible to refine the ideas and develop the project plan on which the proposal will be based.

It is important to be sure that every prospective partner has the capacity and skills to take on the project roles that are suggested. Previous experience of networking or co-operative working is valuable, as it is easier to work with people and organisations that your organisations knows and trusts.

In the proposal, all partner organisations must demonstrate to the EC that they meet governance requirements for managing their finances.

Project partners cannot subcontract their work to other organisations; if a prospective partner does not join the consortium or cannot meet the EC requirements, they cannot be paid later by a project partner to carry out the work assigned to that project partner. However a patient organisation might join the consortium as a 'collaborating' partner to take on an advisory role, or it might allow a worker to take a secondment with a project partner.

Patient organisations may be asked to advise a project consortium on good practice in involving individual patients. We hope they will signpost project co-ordinators to this toolkit.

4.7 SUBMITTING A PROPOSAL

The proposal brings together all the information that the EC needs to assess a proposal, into one large document several chapters long. Although programme requirements are different, the proposal should typically include:

- An analysis of the problem, including the evidence base
- Links to the funding call – how the project idea matches the call and the policy areas identified as priority for that year or funding period
- Objectives – what the project expects to achieve, why, and how the achievements will be measured
- Methods – how each objective will be achieved
- Expected results – the impact the project results could have within Europe, and the deliverables – specific things the project will produce
- Risk and contingency planning
- Evaluation of the project
- Project timeline – showing when deliverables will be ready
- Work packages – a detailed description for each set of activities, including the project co-ordination
- Dissemination – how the project results will be publicised
- Partners – their roles in the project, and their experience
- The budget – for all the project activities.

Checking the requirements for the funding call is essential.

All this information must be submitted before the project deadline; by using tight deadlines for submitting the proposal, the EC excludes applicants who are unlikely to have enough skills, capacity and experience to carry out the project. Partners must also provide details about the governance and financial management of their organisations. This includes copies of the documents through which they are registered as an organisation in their own country.

Some EC funding programmes require the prospective partners to register these documents with the Directorate-General well before the deadline for submitting proposals; it can take some time to get a certified copy, if the documents are in a national register.

Some organisations provide training on writing funding proposals; others provide a proposal-writing service, for which they charge a percentage of the funding awarded if the proposal is successful. This cost, and any others involved in preparing the proposal, must be found by the project consortium. None of these costs can be included in the project budget.

After the deadline, proposals are evaluated by the Commission, and by experts in the topic of the call. The EC keeps a database of people willing to act as experts, and ensures that there is a turnover in the experts performing this role. The evaluation process can take a few months. Sometimes there is a two-stage selection process, and partners may be asked to give a presentation about their proposal.

Joining the EC's panel of experts to evaluate proposals is one way to get experience of EC projects. It may involve working long hours for a short period, which may be difficult for patients managing a chronic condition.

The lead partner is notified of the result of the evaluation by email; if the proposal is turned down, the reasons will be given in the form of a critique, so that the partners receive feedback. If the proposal is successful, the lead partner is invited to negotiate. This means that the Commission is very interested in the project proposal and would like to see the project take place. There is no guarantee at this stage however that funding will be awarded; for example, there may be a check that all the partner organisations are solvent.

At the evaluation stage the Commission may wish to reduce the time taken by the project, and the budget. It is unlikely that funding will be awarded for a long project unless at least some of the partners have taken part in or led a short project successfully.

4.8 STARTING THE PROJECT

Projects usually begin with a launch meeting when some partners may meet each other for the first time. At the launch meeting the project work packages will be reviewed so that each partner understands how their activities in their own countries fit with the overall plan. This is important, as the workers who attend the launch meeting may not be the same people who were directly involved in developing the proposal. There is no opportunity for changing the project design significantly at this stage; the project must deliver what was described in the proposal.

The EC project officer may also attend to explain what expectations the Commission has of the project, the bookkeeping and reporting requirements, and when the funding instalments will be paid. This enables all partners to collect the correct information as they go along, rather than having to scramble to collect the information when the report is due.

An EC project brings together organisations of different types from different countries, to work on projects that the individual organisations could not carry out on their own. Although there will be language and cultural differences, the participants share a motivation to make a difference in their own countries through the project. The launch meeting is likely to be held in the style of the host country, which may be quite different from what the participants expected.

The meeting provides an opportunity to build working relationships; some informal time or working in small groups may help with this. If anyone new joins the project after this meeting, perhaps because they were not recruited in time to attend the first meeting, the project co-ordinator and the partner organisation must make sure that the person receives a good introduction to the project work, and is made welcome in future project meetings. It can be difficult for newcomers to join an established group. This may be especially true for volunteer patients or patient representatives recruited into the project steering group if other partners don't quite understand why the person is there. If the purpose of patient involvement within the project has been clearly explained at the launch meeting, the other partners could be eagerly awaiting the patient's arrival!



The relationships formed during the project may be important after the end of the project. Networking round Europe is important in building a Europe for the future.

4.9 DISSEMINATING THE PROJECT RESULTS

The EC wants all projects which have valuable results to be widely known so that as many citizens and policy makers as possible can benefit. In its proposal each project describes how it will make the results known – its dissemination strategy. This strategy may be carried out during the whole project period, or in some cases during the last few months. As well as making the results known, the project partners may want policy makers to take up their recommendations. In practice, individual partners may continue disseminating their results and/or lobbying after the end of the project.

Value+ research showed that a significant proportion of involved patients felt that they did not receive enough information at the end of the project; in particular, they did not know whether the results of the project in which they had been involved had influenced future policy or health provision.

We suggest that a project's dissemination strategy should include sending a short patient-friendly summary of the results directly to any patients who were involved only in earlier stages of the project, and, through appropriate networks, to grassroots patients. We also suggest that one partner should take responsibility for sending updates to the same patients on any developments – or lack of developments – following any lobbying activities.

If dissemination activities take place in the course of the project, they can be included in the budget. If they take place after the end of the project, then the project partners need to be aware in advance of how they will fund these information-giving activities.

4.10 PROJECT REVIEWS AND REPORTING TO THE EUROPEAN COMMISSION

Reports must be submitted to the project officer at stages during the project, as described in Section 4.3. The project co-ordinator collects the information from the partners and puts it together, showing how the money is being spent, and what progress has been made on the deliverables. The payment of the next funding instalment depends on the Commission's financing office accepting the report; the officer may ask for more information, or hold back money until a particular activity is completed. The final payment comes after the final report typically within three months. This has implications for the partners' cash flows.

Other checks may be made during the life of a project; what they are depends on the funding programme and the length of the project. Project review meetings, for example, are an opportunity to present the work at different stages to reviewers from the EC. Three to five reviewers would attend this meeting, including experts in the project topic; some of them might be the same people who evaluated the project proposal. There may also be a review meeting at the end of the project. Another method is self-evaluation, where project partners carry out the review themselves and send the results to the project officer.

Feedback from the EC to the project will be channelled back through the project co-ordinator.

These reviews are an opportunity for the partners to stand back from the work and evaluate what is happening in the project. Project partners may choose to focus on topics such as the effectiveness of their communication channels, or the quality of their patient involvement, as well as the quality of the project work itself.

Working In Partnership





5.1 CHAPTER OVERVIEW

This chapter looks at how to make contacts outside the patient organisation. It then goes into more detail in discussing links with other patient organisations and then building relationships with health professionals. We then describe how partnerships can work within an EC project, and how to find possible partners for those projects.

Networking means getting to know people in other organisations to exchange information. It increases the patient organisation's knowledge resources by bringing in new ideas, provides examples of how different approaches can be put into action, and widens the circle of people who may have answers to the organisation's challenges or recommend information sources. It is an opportunity to create links with other organisations which may become the basis for future co-operative working. It could mean more is achieved with the same resources or that the patient organisation's everyday activities run more smoothly, because of better working relationships with the professional groups with which they come into contact. It could also mean that something is achieved which could not be achieved by one organisation alone.

Findings from Value+ indicate that patients, health professionals, and other stakeholders working together can achieve outcomes in health-related projects which are not possible for patients or the other professionals working alone.

Many things may stand in the way of networking and linking; different languages and cultures, competition between patient organisations, lack of opportunity or interest, different agendas.

Even when people speak the same language, they may attach different meanings to the same words, or not understand the specific meaning for common words that are used by people working in a specialist area. This special use of ordinary words is often referred to as 'jargon'. For example, a worker from a patient organisation speaking to a health professional may refer to 'patients', meaning people in hospital, 'service users', meaning people with the same condition living at home and accessing health and care services, and 'clients' meaning people anywhere with the condition who choose to use the patient organisation's services. To the health professional, all these people are 'patients' and the differences between these groups of people are not understood unless they are explained.

"Nothing could be more important than to have both experts and patients"

Project co-ordinator, ECORN-CF

Language difficulties are increased when people communicate in another language. Sometimes the only common language is one that is foreign to both speakers, so there are more opportunities for misunderstanding.

Any organisation develops its own culture and working methods, which are accepted as the way to do things within the organisation. As hospitals and health authorities are usually much bigger than patient organisations, their cultures are very different even before considering other factors, such as the history of the organisations and the training of their workers.

Workers are likely to feel most comfortable networking and linking with organisations with a similar culture to their own. Building links with organisation with a different culture is more difficult. It is important to find and build on similarities, rather than being discouraged by the differences, and to look beyond the limits of both organisations to see what could be achieved together.

There may be common ground in the aims of both organisations; for example, both may aim for the best possible healthcare for their patients. They may share the same values, even though the organisations demonstrate them in a different way because of their different roles with patients. Organisations may have very different agendas; while one may be focused on providing services to patients, and another is focused on research, they may still find common ground. When all parties see enough benefit in the networking and linking activities to invest work and time, cultural difficulties can be overcome.

Patient organisations may be in the position of competing – to win a tender to run services, to get funding, to recruit members. There may be good reasons for this competition; they may represent different patient groups, whose interests are not the same. They may work from different values.

Some patients have described to us how they feel when patient organisations compete. Sometimes they see that the competition between two organisations uses scarce resources that could have been used more directly for patients. Grassroots patients may not know the full story behind the rivalry between two patient organisations. However, the organisations' focus on their own rivalry rather than on patient needs may discourage grassroots patients from becoming involved with either organisation.

5.2 LINKING WITH OTHER PATIENT ORGANISATIONS

Patient organisations come in all sizes, from small local groups to organisations that work at a European level. Small local groups can become part of larger organisations operating at regional or national level. National patient organisations may form an umbrella organisation with other patient organisations in the same country that represent other conditions; an example is the Spanish Patients Forum. National patient organisations may also take part in European or world umbrella organisations with other patient organisations for the same condition in other countries; an example is the European Network of (Ex-) Users and Survivors of Psychiatry, which is in turn a member of the World Network of Users and Survivors of Psychiatry.

All these levels of organisations and activities offer communication channels and networking opportunities through meetings, newsletters, email lists, and so on. Taken together, the different levels provide a unique communication channel between grassroots patients and policy makers. Though many patients never join a patient organisation of any kind, they can keep themselves informed through websites and newsletters, and come forward to contribute their views or participate when something interests them.

“I emailed other organisations and no-one replied. Please ask people to reply, even if the answer is no. People are waiting on the answer”.

Value+ focus group participant, on the topic of networking

Organisations and groups may be active in research, lobbying health policy makers, providing information and services to patients. This shows that the aims and activities of patient organisations vary widely from each other.

Rather less obvious may be the different values which underpin the organisations. These different values are very important to patient groups when deciding whether to become a member of a larger patient organisation, or link with another organisation to carry out a specific activity.

Attitudes to funding and to representation are two examples of the effects of holding different values:

- Some patient organisations refuse to accept funding from sources associated with therapies that could be harmful to their patients, or from sources that could appear to indirectly influence individual patients' treatment decisions. Linking with an organisation that did not share these same values could affect the patient organisation's public image, and could lose the support of grassroots patients.
- Patient organisations represent patients in different ways; these can be by getting views directly from patients, or from patients and carers, or by supporting carers to put forward the patients' interests when the patients cannot do so themselves. Though the interests of patients and carers are often similar, patients and carers do not always agree on choices about treatment and care. For example, a carer may prefer to limit a patient's activities while the patient may wish to develop more independence. Parents may still identify themselves as carers when the child is adult and living independently. In some countries parents may still influence the treatment of adult children who actually have the mental capacity to make their own decisions; this can happen through mental health legislation. The patient/carer distinction is not important for many patient organisations. However some organisations accept only patients as members and may prefer not to work closely with organisations run mainly by carers.

Patient organisations have usually grown from groups of motivated patients and/or their families, working for the benefit of patients. They may sometimes be in competition with each other for funding. Nevertheless patient organisations are usually very ready to support other organisations with the same aims, when they can see a benefit to grassroots patients. When values are compatible with another patient organisation, networking contacts can identify shared interests and activities where co-operation is beneficial to both organisations.

Co-operation can happen at a local, national or international level. Co-operative activities might include:

- Sharing expertise through leading a training workshop at the other organisation's event
- Making resources go further by developing and delivering training together
- Linking websites so that patients with one condition can easily find information about other conditions associated with their diagnosis
- Forming support groups for workers with people from other organisations doing similar work
- Increasing the impact on policy makers by lobbying together.



Networking and linking are of course limited by the resources available to the patient organisation; unless funding is obtained for specific co-operative activities, it may be seen as a low priority. Nevertheless, if another patient organisation makes contact with yours, it is important to your organisation's image that they receive a reply. In fact any contact that a representative from your organisation has with anyone outside your organisation contributes to your organisation's image; make sure people outside the organisation see a strong organisation that could be a reliable partner.

The EC encourages co-operative working between countries; an organisation's experience of co-operative working with another organisation may be relevant for a funding proposal. Other funders too may look favourably on a proposal from organisations working in co-operation, when each organisation working alone would not have enough knowledge and experience to deliver what was required.

5.3 BUILDING RELATIONSHIPS WITH HEALTH PROFESSIONALS

Health professionals and scientific researchers, even though they may be patients themselves, have a different background from most of the patients with whose condition they work. Their training is regulated by professional organisations which set standards, for example in medicine, nursing, or physiotherapy. The training has a strong scientific focus and, in the case of doctors at least, it allows little time for learning communication skills; these are developed 'on the job'. Their contacts with patients are focused on the patient's illness and need for care, and they may not see for themselves how competent and effective the same patients are when their health is better. For all these reasons, the benefits that patient involvement can bring may not be obvious to them. They may not even understand that patient involvement is different from using patients as research subjects.

"Build relationships with patients before you want to involve them in a project, so that when you need them, the links are already there".

Value+ focus group recommendation to doctors

By attending training sessions together, providing training for each other, working together on local advisory groups, patients and health professionals can get to know each other in working roles. If they are willing to listen to each other openly, cultural differences can be overcome.

Patient organisations can ask health professionals to join their trustees or an advisory panel giving them clear tasks such as reviewing new papers relevant to the condition the organisation represents. This helps the patient organisation update its information, and gives it an opportunity to reply to the scientific papers from the patient perspective if it wishes. As with your other volunteers, keep the health professionals motivated, and make sure you inform them about positive impacts from their work.

Four Swedish patient organisations have joined together to train patients as researchers. The trained patient researchers are joining projects funded by the patient organisations. The project reports that the number of patients wishing to take up the training has been overwhelming. For further information, see www.forskningspartner.se

The European Patients' Forum holds regular regional seminars in different European locations, where representatives from individual member organisations lead workshops. See www.eu-patient.eu/

Health professionals who are involved in the work of patient organisations are valuable allies, and they can promote the patient organisation to colleagues who have contact with patients. This makes it more likely that information about the patient organisation reaches new patients shortly after diagnosis. Supportive health professionals also increase their colleagues' understanding of patient involvement itself.

"It felt like they were shouting at us all the time, so I couldn't really take in what they were saying".

Academic, after attending a training delivered by patients

When health professionals resist approaches by patient organisations or requests for patient involvement, find out why and address their concerns. Perhaps a previous experience of patient involvement has been unsuccessful in some way, and you may need to show why what you are suggesting will be different. Health professionals are especially careful to protect patients within their profession's ethical guidelines; patient organisations may need to demonstrate their own ethical approach. The friendly and informal tone and everyday language used by patient organisations to support communication with grassroots patients can mislead health professionals; they may get the impression that the patient organisation is ill-informed and badly organised. Disillusion them!

Consultations and other patient involvement activities sometimes provide a platform for angry patients to shout at health professionals or policy makers. Calmer patients may be so determined to get their point across that they constantly repeat the same thing without listening to the replies. Support patient involvement by ensuring that any patient representatives you send to meetings have adequate training in communication skills and model the behaviours you recommend to others in guidelines for involving patients in meetings, such as listening with respect.

For patients, doctors in particular may represent authority. Older patients may even believe that they should not ask questions during their health consultations; after all, if the doctor felt the patient should know something, s/he would tell them without being asked. There is also the hope and belief that the doctor is so powerful s/he can cure the patient, and since s/he is so powerful, obviously s/he knows everything about the patient's condition without the patient having to give details.

In health-related projects patients may come into contact with health professionals who are in a research role, rather than in a clinical role. The patients themselves will be in a worker role connected with the project activities. In order to achieve the equal relationships that patients see as the basis for successful involvement, the patients need to communicate adult to adult with health professionals. The health professionals need to recognise the patients as colleagues, to whom the ethical codes designed for treating patients or using them as study subjects do not apply.

The International Patient Organisation for Primary Immunodeficiencies (IPOPI) organised the EU Primary Immunodeficiency Consensus Conference on the diagnosis and management of Primary Immunodeficiency disease. The conference brought together experts, European Union and national agencies and health ministries, researchers, professional organisations and patient groups; some of the patients addressed the conference. The results of the Primary Immunodeficiencies Consensus Programme can be applied in many countries. See www.ipopi.org

5.4 PARTNERSHIP IN PRACTICE

This section is relevant for any activity or project, not just EC-funded projects, where patient organisations work with partners who may or may not be patient organisations.

When forming a partnership, potential partners need to identify the opportunities and risks that could come from joining with the other organisations. Do the potential partners' aims and values fit with each other? Do they have sound financial management? Can they recruit and support enough skilled workers? The Value+ tool 'Is this the right Project for our organisation?' may help with this decision.

See Section 6.3 'Is this the Right Project for Our Organisation?'

At the planning stage project partners identify what each will bring to the proposed activity or project, and divide up the responsibilities. What can patient organisations add to health-related projects which include health professionals and partners from other specialist sectors? What are the roles that only patients can take, and the activities where patients can make a unique contribution?

Patient organisations may be much smaller than their partner organisations, both in terms of the amount of money that passes through the organisation in a year (financial turnover) and the numbers of people they employ. In a patient organisation, there are usually fewer layers of management between the Chief Executive Officer and the workers who work directly with patients, than there are in many health settings. This often means that the CEO of a patient organisation gets information from and about patients more quickly than their counterparts in organisations that provide healthcare.

This information is different in quality, because patient organisations may have more time to listen. Patients describe their experiences in a different way to someone who they know has experienced something similar. Because of the fear that care may be withdrawn if the patient is not suitably grateful, some patients find it easier to express doubts and dissatisfaction to someone who is not involved in providing their healthcare. When a patient organisation hears these doubts and dissatisfactions, it can often provide information that puts the situation in a new context. By talking the situation through, they may enable the patient to take up their concerns with the people providing their healthcare.



This special communication and understanding with grassroots patients enables patient organisations to represent the patient perspective on the project Steering Group. They can bring that perspective into planning what the project does and how to do it, and ensure that the project results meet patient needs. Patient organisations can advise on the design of questionnaires, interview schedules, written information and presentations for patients both about the project and the project results. Representatives from the patient organisation can bring an extra dimension to carrying out these tasks and others, such as recruiting workers and volunteers for the project, holding focus groups, interviewing patients, reporting to funders, presenting the project results and communicating them widely, and lobbying policy makers. Patient organisations may also take part in other tasks within the project for which a patient perspective is not essential, but for which they are qualified through employment experience rather than patient experience.

The Value+ tool 'Capacity and Skills for an EC Project' can be applied to any project to help identify how the partners will meet the project requirements together.

See Section 6.3 'Capacity and Skills for an EC Project'.

Patients and project co-ordinators have stressed that patient involvement should be based on equality, with patients as equal partners in a project. It takes a deliberate effort to think what equality really means, and how it can actually happen.

"To be meaningful, patient involvement needs to be understood and accepted by the professionals as a "win-win" situation. Accept the fact that working all together, sharing ideas and suggestions as a "global team" can be the solution to achieve a better education in treatment, better understanding of each other, offer better chances to improve patient's quality of life and therefore delay complications in the disease etc..."

Value+ focus group participant

The Swedish Forskningspartner (research partner) project has produced two sets of guidance. One is for the patients it has trained as research partners, to help them work in research projects. The second set of guidance is for researchers in the projects that the patient research partners will join.

As project partners are likely to have different training, experience, and working methods, they do not start out from the same place. For example, some project partners may be used to having a large budget, while others carry out their activities with limited money. Workers from most partner organisations are paid, while representatives from patient organisations sometimes do some or all of their work as volunteers, fitting it in with family and employment responsibilities. Patients and patient representatives may feel that clinical members of a project team could influence the care that the patient or the patient representative's relative receives, even if this is not possible or likely. Patients and patient representatives have an intimate knowledge of the condition and how it affects everyday life round the clock. All these factors, and more, affect equality within the project.

The presence of a patient in a project steering group does not in itself ensure equality; patient representatives need enough confidence and knowledge, both about the project and the patients they represent, to take part in project discussions. Other partners must be willing to listen to them with an open mind. A commitment within the project to equality may include larger financial contributions from some partners, scheduling meetings and events so volunteers find it easier to attend, and training sessions on specific issues by project partners, including patients, so that all partners have an increased understanding of the specialist areas important to the project. Sharing training together can be a valuable opportunity to build understanding between partners; when this understanding exists, communication becomes easier.

For 'This is what you need to think about as a patient research partner' see Section 6.4.

For 'What you need to think about when engaging a patient research partner' see Section 6.4.

It is inevitable that during a project frustrations will arise; what is important is the way these are handled. For example, small patient organisations can be flexible and change quickly in response to their members; they may be frustrated at the time it takes for several partners working together to come to decisions. Good planning and communication at the start of the project, including establishing what each partner expects, will reduce the problems that arise and help to manage the ones that do. Risk management planning can ensure that most problems that do come up do not bring the project to a halt.

5.5 HOW TO FIND POSSIBLE PARTNERS

Before you look for partners, review what you want partners to do, and draw up some criteria. The Value+ tools described in the previous section can help focus your ideas.

Have a clear proposal to discuss with potential partners. Although the proposal may change later during negotiations with potential partners, it demonstrates that your organisation has an ability to plan, and a good understanding of patient needs and the project topic. This shows that your organisation can be a strong project partner.

Your organisation may already have strong local or national links with research institutes, health professionals' organisations, individual clinicians, other agencies that provide services to the same patients, other patient organisations and industry. Consider whether any of these existing contacts would be suitable partners.

Although it may be more difficult to build links with organisations in other countries than in your own country, European patient organisations provide communication channels for their members. The European Patients' Forum provides networking opportunities through its seminars, other events, and newsletters. Consider also whether the people you already know in research institutes or clinical settings have access to communication networks which could put you in touch with suitable partners in other countries.

For EPF Directory of European and National Patients Organisations go to www.eu-patient.eu/projects/valueplus/directory

Resources





6.1 CHAPTER OVERVIEW

This chapter contains tools and resources developed by the Value+ project, including the Value+ Literature Review. There is also a Directory of European and National Patient Organisations, and an overview of patient rights in different Member States, both prepared by the European Patients' Forum. We also include information and tools from other organisations, and a list of websites and literature.

We have consulted widely during the Value+ project; patients and patient organisations have taken part in developing and trialling our tools. We have included some of their comments on individual tools, and changed others following their recommendations.

The chapter starts with a topic that was clearly important to all the patients and patient organisations with whom we came into contact during the Value+ project. That topic is examples of good practice which show what patients working together can achieve.

As many patients know from finding out how to manage their own conditions, the example of how to do it may not be as important as the knowledge that it can in fact be done. Knowing that something is possible is a great encouragement.

6.2 EXAMPLES OF GOOD PRACTICE ON PATIENT INVOLVEMENT FROM EUROPEAN AND NATIONAL PROJECTS

During the project, the Value+ team had contact with many completed and ongoing projects. Many of them had interesting features from which other patient organisations may learn and we share them in this section focussed on good practices on patient involvement.

The Value+ project had originally planned to highlight some showcase examples of patient involvement in EC-funded projects. However, we felt that selecting only a limited number of examples we would not be fair in sharing the variety of good practices coming from other projects.

For this reason, in this section we provide a brief description of these projects and some features which are interesting for patient involvement. All these projects were supported by EC-funding, unless we state otherwise in our description.

This section demonstrates the wide variety of projects in which patients and patient organisations become involved.

We organise these projects by:

- Projects which involve individual patients
- Projects with a patient organisation/s as partners
- Projects led by patient organisations.

Projects which involved individual patients

- The **Alladin** project developed technology for use in neurorehabilitation, particularly with stroke patients, to assess and support functional recovery. Patients were given a small number of sessions with a machine which presented them with a virtual scenario and asked them to try to do a simple task, for example, to lift something they could see on a screen in front of them. As they tried, patients could then see their arm move on the screen in front of them, even though physically they had little or no movement. Patients reported that using the machine motivated them to persist with their rehabilitation. www.alladin-ehealth.org/
- The **Migraine and Chronic Daily Headache Management – The Patients' Perspective** project developed training for patients, focusing on coping strategies and relaxation techniques. This project also trained patients to become trainers, so that the techniques could be widely spread by trainers who really understood the problems.
- The ongoing **Remine** project is an IT-based project, aimed at identifying potential risks to individual patients when they are hospitalised. Risks are not always recognised because the patient's health records are not always quickly available, and it is difficult to extract all the relevant information from them. The Remine project had no patient organisation partners, and wanted information about how to involve patients better in the ethical decision of allowing their records to be analysed before the point when they might be in immediate need of hospital care. We considered their commitment to learn about patient involvement as the first step to good practice in involving patients. The patient group in which they were interested were elderly patients, some of whom would not have the capacity to understand the consent procedure. www.remine-project.eu/

The Value+ team suggests that when individual patients lacked mental capacity, the project could work with any relatives, carers, care workers, patient advocates or other independent organisations which provided information or services to the target patient group.

This would mean involving representatives rather than patients, as patient involvement itself was not possible. Alzheimer Europe's website provides information about the law on mental capacity. www.alzheimer-europe.org/

- The ongoing **SWEET** project is developing centres of reference for the treatment of children and adolescents with diabetes. It is also developing child-friendly information, and planning to hold a focus group with children who have diabetes. <http://sweet-project.eu/html/en/index.html>
- The **GENDEP-ELSI** project involved researchers who were also patients, through the Service User Research Enterprise at the Institute of Psychiatry, Kings College, London. The study looked at the ethical and social implications of the GENDEP clinical trial with pharmaceuticals for depression which are adapted to an individual's genetic make-up. The study held focus groups with patient who had taken part in the trial, to explore their views and check whether patients had understood the consent form for the clinical trial. www.iop.kcl.ac.uk/projects/?id=10192
- The **Comoestas** project aims to develop an innovative computerised system that allows patients with Medication Overuse Headache to receive continuous and personalised treatment. The system will be based on an advanced Alerting and Decision Support System that follows patients from the diagnosis and supports the physician in managing the therapy and controlling relevant events impacting on patient safety. The project involved patients in developing a questionnaire for a study aimed at assessing patients' need and preference about different source of information and expectations of headache treatment. www.comoestas-project.eu
- The ongoing **Translational Research in Europe – Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)** project is a network of 21 partners in 11 countries. It aims to establish best practice in the diagnosis and care of neuromuscular disease patients, and to promote research into new treatments for these rare disorders. Patient organisations started the project, provided part of the funding, and are leading it. www.treat-nmd.eu/home.php
- Co-operation between research clinicians and a patient association, Mukoviszidose e.V. Bundesverband Selbsthilfe bei CF in a pilot study led on to the ongoing **European centres of reference network for cystic fibrosis** project (ECORN-CF). This project provides expert advice on cystic fibrosis to patients, doctors and carers all over Europe so that it is the expertise which travels, not the patient. This project's work is already being used as a model for the transfer of knowledge and expertise on rare diseases in EU Member States. The project will produce information in eight languages. <http://ecorn-cf.eu/>
- The ongoing **European Union Network for Patient Safety (EUNetPas)** project aims to improve co-operation between European Member States to develop patient safety programmes, provide rapid response to health threats, prevent medication error, produce guides and competencies for health professionals, and share expertise to develop a sustainable network for patient safety in the EU. <http://90plan.ovh.net/~extranetn/>
- The ongoing **European network on endometriosis (ENE)** project seeks to raise understanding and promote awareness of the impact of endometriosis across the EU, and to create an international network of expertise and opportunities for all professionals and individuals dealing with the disease. Information and support will be aimed at individuals, researchers and academics, health professionals, and employers. www.endonetwork.eu/

Projects with a patient organisation/s as partners

- The **Edupark** project aimed to improve the quality of life of people with Parkinson's disease, by organising sessions where patients shared and improved their coping strategies. Patient organisations helped to shape the design of the sessions, and participant feedback also contributed to the session design. Patients reported that meeting others with the same condition, and learning from each other, was very motivating. Patient organisations helped to publicise the project results to grassroots patients.
- The Mental Health Europe project '**Good Practices for Combating Social Exclusion of People with Mental Health Problems**' included mental health organisations from ten Member States. The project partners analysed the situation of social exclusion of people with mental health problems in each of the partner countries, and identified local examples of good practice working towards social inclusion. Some of these examples are included in Section 3.5.2. Patients themselves were consulted as experts and chose the best practice examples. www.mentalhealth-socialinclusion.org/home.html The Slovenian website for support with depression, reported by this project, is www.nebojse.si



Information gathered during this project led to further local and national initiatives. Mental Health Europe has received core funding and recognition as a key network involved in the fight against social exclusion of people with mental health problems.

- The **Salut** project developed Internet-based systems to improve diagnosis and services for eating disorders. Internet-based therapy is now available and in use. Patients and patient organisations validated an online self help guide for bulimia which was developed during the project; the information is available in English, French, and Spanish. See www.salut-ed.org/
- The **SEEM II** project addressed health and social services for elders from ethnic minorities; they were not patients with a specific condition. The Value+ team included it because it was the only project we discovered which specifically addressed diversity issues in health and social care. In Romania, the project's aim was to develop training programmes for young Roma women to give them the skills, experience and knowledge needed to work in the health and social care sector. This would serve the major goal of improving access to those services for the Roma community and voicing the needs and concerns of the Roma as a whole and Roma elders in particular.

Projects led by patient organisations

- “Our organisation – APOZ - Bulgarian Cancer Association and friends – was approached by the government and Ministry of Health because they had no idea what number of people needed what level of treatment (early stages to advanced). We initiated research to help find this out but received no payment at all; it was all done on a voluntary basis. It was a big success and the government understood that they needed to increase financial support. The budget increased by 30% so the situation got better as a result of this work on statistics”.
- The **EU Primary Immunodeficiency Consensus Conference** project, lead by the International Patient Organisation for Primary Immunodeficiencies (IPOPI), aimed to provide a public health model for dealing with primary immunodeficiency disorders in the EU. The information produced by the project was presented at the conference, and translated into ten languages. www.ipopi.org
- The European Federation of Allergy and Airways Diseases Patient Associations (EFA) gathered information, using their member associations and consultants in different countries, about the quality of indoor air quality. Air pollution is a big factor in some allergies and airways diseases, and many people spend most of their time indoors. Their project ‘Towards Healthy Air in Dwellings in Europe’ made recommendations that would decrease this air pollution. www.efanet.org/activities/documents/THADE.pdf
- In 1997-2000, Alzheimer Europe’s **Lawnet** project collected all legislation relating to the rights and protection of people with dementia in the European Union. The results were used in two ways; the first was to inform people with dementia and their carers about their rights. The results were also used as a means to improve the legal rights and protection of people with dementia by using them as an evidence base to draft legal recommendations. The legal rights tab on Alzheimer Europe’s homepage www.alzheimer-europe.org/ gives access to reports of the legal status in each country.
- The Lithuanian Multiple Sclerosis Society (LISS) worked with the Danish Multiple Sclerosis Society on the **Challenging Multiple Sclerosis** project, adjusting the most effective Danish models and experiences to Lithuania and helping to prepare a Lithuanian strategy of providing help for people with multiple sclerosis. The project held events to raise public awareness, and an annual conference for patients and professionals together. Another outcome of the project was the increased contact with other patient organisations for multiple sclerosis in other Baltic States, leading to a strong patient lobbying group in this region. www.liss.lt/index.php/pageid/574
- The ongoing Swedish Rheumatism Association, the Swedish Asthma and Allergy Association, the Swedish Heart and Lung Association and the Swedish Psoriasis Association have come together in the **Forskningspartner** (research partner) project, which is not supported by EC funding. They are training patients to join research projects as patient researchers. www.forskningspartner.se/start.asp?sida=5590
- The **Multiple Sclerosis – the Information Dividend (MS-ID)** project aimed to improve access to treatment and quality of treatment for all citizens affected by multiple sclerosis. The project reviewed methods of social support as well as good practice in diagnosis, treatment, and management. The project was led by the European Multiple Sclerosis Platform, which is now lobbying for action on their recommendations. These include a European Code of Good Practice. www.emsp.org

- The Establishment of a network of Specialised centres for children and young people within ASD Autistic Spectrum Disorders project was initiated by the Bulgarian Association Autism to develop services to meet the needs of patients with autism. The patient organisation developed patient/family friendly leaflets and website content. Although involving patients themselves was not easy, the project noticed that the patients' skills and confidence increased through their work on the project, and their relationships with health professionals appeared to improve.
- The Euroguide project has gathered information about genetic testing, counselling and research across Europe, involving patient organisations and reaching grassroots patients through an online survey. www.euroguide.org.uk/
- The Asthma School project was started by an organisation of mothers of children with asthma from the Abba Association. They developed training sessions which are delivered by mothers themselves, and published a booklet which has a chapter on "Children with Asthma". "Our experience shows that publishing of this kind of teaching materials including the knowledge of both professionals and patients is extremely useful, because it includes the experience of the parents and patients shared in a very easy to understand manner and supported by the professional and scientific explanation of the medical experts".
- The Proretina SND project was started up by patients, who also led the project. Self-help groups were set up for patients with eight rare retinal degeneration conditions. Focusing at first on supporting each other and sharing coping skills, the patients involved then identified other topics on which they wished to work; these related to healthcare, information for patients, and research. They developed a description of the conditions, and a structured file to support patients' communication with their doctors about their diagnosis and treatment. They also developed a training film for doctors to show them how the patients' self-advocacy and self-help could support better communication with doctors, and better self-management of the condition. www.pro-retina.de/

6.3 VALUE+ TOOLS

This section contains tools developed during the Value+ project for patient organisations to use.

VALUE+ MODEL OF MEANINGFUL PATIENT INVOLVEMENT

Described in Section 2.6.3.

VALUE+ INDICATORS FOR MEANINGFUL PATIENT INVOLVEMENT

Described in Section 2.6.4.

ASSESSMENT GRID OF THE VALUE+ MODEL OF MEANINGFUL PATIENT INVOLVEMENT IN PROJECTS

Described in Section 2.6.5.

VALUE+ LEVELS OF PATIENT INVOLVEMENT IN PROJECTS

Described in Section 2.6.5.

VALUE+ POLICY RECOMMENDATIONS TO THE EUROPEAN INSTITUTIONS

Developed by the Value+ Steering Group and revised by various patient organisations and stakeholders.

VALUE+ POLICY RECOMMENDATIONS PATIENT INVOLVEMENT IN HEALTH PROGRAMMES AND POLICY

Background

The Policy Recommendations on Patient Involvement in Health are one of the results of the two-year project "Promoting Patients' Involvement in EU Supported Health-Related Projects – Value+" co-funded by the Public Health Programme. Value+ is based on the premise that the meaningful involvement of patients enhances the outcome of health projects, and through that patients can contribute effectively towards patient-centred, equitable healthcare policy throughout the European Union (EU). The focus of the project was thus to assess the status of patient involvement and to exchange information, experiences and good practice among key stakeholders.



Value+ confirmed the added value of involving patients in projects and policy in particular with regard to two fundamental aspects: patients have unique expertise due to living with a specific condition and their experience of healthcare; patient involvement contributes to a more transparent and democratic health policy making process.

We acknowledge as very important steps, policy developments at the European Commission (EC) level regarding inclusion, participation, and empowerment of citizens and patients. Amongst them:

The White Paper **Together for Health: A Strategic Approach for the EU 2008-2013** (October 2007) highlights that citizens' and patients' participation and empowerment need to be regarded as core values in all health-related work at the EU level. *"Building on the work on the Citizens' Agenda, community health policy must take citizens' and patients' rights as a key starting point. This includes participation in and influence on decision-making, as well as competences needed for wellbeing, including health literacy"*¹. It is clearly recognized that citizens' empowerment can also be supported by civil society, including patients' groups and disease support and advocacy networks.

Patient involvement is also one of the operating principles put forward in the **Council Conclusions on Common Values and Principles** in the European Union Health Systems (June 2006): *"All EU health systems aim to be patient-centred; this means to involve patients in treatment and therapies, to be transparent, to offer them quality information and choice"*².

By grouping various healthcare related initiatives focused on patients into a single package, the Europe for Patients campaign moves towards achieving stronger patients' empowerment.

The **Council of Europe Recommendation No. R (2000) 5** on the development of structures for citizen and patient participation in the decision-making process affecting healthcare, recommends the governments of Member States *"to ensure that citizens' participation should apply to all aspects of healthcare systems, at national, regional and local levels"* and (...) *"create legal structures and policies that support the promotion of citizens' participation and patients' rights, if these do not already exist"*³.

The Value+ project acknowledges the enormous progress represented by these milestones and the advances related to patient involvement achieved at many levels and in various health arenas. Nevertheless, there remains the concern that there is still a tokenistic approach to patient involvement. Value+ assessed a number of important areas where improvement is needed to achieve what The European Patients' Forum (EPF) defines as **meaningful** involvement of patients and patient organisations:

Meaningful Patient Involvement means that patients take an active role in activities or decisions that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients. The involvement must be planned, appropriately resourced, carried out, and evaluated, according to the values and purposes of:

- The participating patients or patient organisations
- Other participating organisations and funding bodies
- The quality of their experiences during the involvement activity.

This definition can apply to involvement of individual patients or patient organisations in participatory or patient-led activities. It relates also to involvement of family members and carers acting as patient representatives where the patient is unable to represent himself/herself.

Value+ looked at involvement in projects exploring also how gender affects the involvement of patients. While it is clear that other issues of diversity must also be taken into account (e.g., ethnicity, disability), the gender parameter was examined in most detail as it plays a major role in the involvement of all patients regardless of other diversity criteria. Important benefits could be found from this approach if the generally limited understanding of the importance of gender in this context could be overcome. Value+ has therefore decided to include gender considerations in these recommendations.

Although the focus was on projects, the Value+ findings go beyond the specific project context and give important insights on involvement at programme and policy levels.

Meaningful and sustainable patient involvement can only be achieved through political commitment, changes in values and attitudes and institutional, structural and financial support and mechanisms.

1 http://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf (Page 4)

2 <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF> (Page 3)

3 <https://wcd.coe.int/ViewDoc.jsp?id=340437&BackColorInternet=9999CC&BackColorIntranet=FFBB55&BackColorLogged=FFAC75>

These recommendations have been formulated as a result of the evidence emerging from Value+ and also through consultation with patient leaders at regional seminars in Lithuania in 2008 and Sofia in 2009. EPF member organisations and health stakeholders have also provided their input and views.

THE RECOMMENDATIONS

The recommendations outlined below are addressed to the European Commission, the European Parliament and the Member States. However, other health stakeholders⁴ have a key role to play in patient involvement and EPF shall be appealing to all of them to sign up to the recommendations in the spirit of partnership and dialogue.

These recommendations are the result of the findings of Value+ in relation to the assessment of patient involvement in health projects supported by the EC. They highlight the views of patients and patient representatives who expressed, through a survey, focus groups and seminars, the actions needed at various levels to achieve meaningful involvement. They are clustered around three themes that are key to achieving meaningful involvement of patients:

- The right to involvement
- Resources
- Capacity building.

The policy recommendations have not been numbered based on priority. They are all equally important.

Value+ has developed a number of tools that could support the implementation of the recommendations:

- Value+ Model of Meaningful Patient Involvement: Definition, Key Areas and Indicators, Assessment Tool, Levels of Involvement
- Toolkit for patient organisations and patients to support their involvement in projects as leader and partners
- Handbook for project coordinators and leaders of organisations aspiring to involve patients and patient organisations in their projects and activities.

The right to involvement

Whereas the right to participation of citizens in public life is well established, the same cannot yet be said about the right of patients to be involved in health related decision making. At the European Union and Member States' level, there exist legislation and policies around patients' rights. These, however, cover primarily medical and ethical aspects, and there is a lack of policies on the rights of patients to participate in decision-making; policy development, programmes and projects.

EPF calls on the European Commission, the European Parliament and the Member States to:

1. Develop, adopt and promote a policy instrument on patient involvement – also addressing diversity issues and the gender dimension of involvement – to be applied at European Union and Member States' levels.
2. Set a mechanism and guidelines to ensure sustainable patient representation in health committees/bodies, decision-making processes (local, national, European).
3. Develop/promote the adoption of a code of practice defining principles and values for working with patients and patient organisations as equal partners.
4. Set up monitoring and evaluation systems of patient involvement in:
 - EC-funded programmes and
 - Policy consultation processes at EU and Member State level.

These systems should include indicators linked to diversity issues and gender.

This recommendation has synergies with Recommendation 5.

Resources

In order to be meaningful and sustainable, patient involvement needs financial, structural and institutional support. Financial resources earmarked for patient involvement are needed as well as appropriate mechanisms and support systems to access them.

⁴ Health professionals' associations; researchers and academics; hospitals, patient organisations; industry, insurers, etc.



EPF calls on the European Commission, the European Parliament and the Member States to:

5. Establish patient involvement as an eligibility criterion for project funding in EC health-related Calls. This criterion should be evaluated by the expert teams in charge of assessing and selecting projects – patient representatives should be involved in the teams. Guidelines for applicants and evaluators should be developed for this purpose.

Patient involvement should also be required as one of the terms of reference for the process review and outcome evaluation, which the projects are required to undertake.

This recommendation has synergies with Recommendation 4.

6. Reinforce the mandate and capacity of bodies/offices in Member States delegated by the EC to be contact points for specific funding programmes so as to enable them to provide guidance and information to patient organisations.
7. Waive the co-financing percentage for patient organisations in EC Calls in consideration of the fact that they are not-for profit; most of them are run by volunteers and often do not have access to loans or bank guarantees due to their annual turnover.
8. Simplify application procedures and set up specific Calls for small size not-for profit organisations and other types of organisations that have limited capacity to meet eligibility criteria of current programmes.
9. Strengthen opportunities for patient organisations to access funds from the European Social Fund and the European Regional Development Fund by:
 - Increasing awareness and visibility about health being now among the priorities of those funds
 - Earmarking a percentage of funds for not-for profit non-governmental organisations (NGOs) and simplifying application procedures
 - Providing good practice guidelines for public authorities in charge of managing the funds
 - Monitoring how Member States administer funds with a view to transparency and equity in healthcare.
10. Increase access to resources at Member State level by: setting up funding schemes for NGOs; reducing taxes for companies/individuals making donations to NGOs and reducing taxation to NGOs.

Capacity Building

Involving and being involved meaningfully is a challenge; various types of knowledge and skills are needed for all the stakeholders. There is often poor know-how related to patient involvement within the EU Institutions, the Member States, health stakeholders like hospitals, universities, researchers, health professional organisations, and patient organisations themselves. This is strongly reflected in the lack of mechanisms for planning, implementing and evaluating patient involvement.

EPF calls on the European Commission, the European Parliament and the Member States to:

11. Invest in a European Centre of Excellence on Patient Involvement led by patient representatives involving a Network of Experts to ensure:
 - Sharing of knowledge and transfer of best practices for patient involvement
 - Wider dissemination of projects' results so that they are delivered to grassroots patients in an accessible way.
12. Establish Patient Involvement Units in the EC and Member States to provide information, guidance, good practices and capacity building. The units would make the liaison between the European Centre of Excellence on Patient Involvement and stakeholders at national level.
13. Invest in capacity building programmes for patient involvement targeted to EC and Member States' policy makers and civil servants, health professionals, researchers, project coordinators, patients and patient organisations and other key stakeholders of the health sector.

VALUE+ LITERATURE REVIEW

The executive summary is in Section 6.6 while the full document is in www.eu-patient.eu/projects/valueplus/resources/attached_documents/valueplus-literature-review-on-patient-involvement.pdf

VALUE+ GENDER AND PATIENT INVOLVEMENT IN HEALTH PROJECTS

This is an Information Sheet developed by the European Men's Health Forum and the European Institute of Women's Health.

Background

The aim of gender considerations in relation to health is for men and women to be treated equally where they have common needs while at the same time addressing their differences in an equitable manner.

Sufficient attention has not been given to gender in health projects, particularly with regard to patient involvement. There are no clear EU guidelines to support gender considerations for patient involvement in health projects, and research on gender and health is still developing. It is hoped that the information in this Information Sheet will support more informed considerations of gender and of the way in which they can enhance meaningful patient involvement.

What is gender?

Women and men are different as regards their biological make-up ([Sex](#)). Men and women's biological susceptibility to disease and response to treatment can be different. Some examples of sex characteristics: women can menstruate while men cannot, men have testicles while women do not.

[Gender](#) refers to men and women's different roles and responsibilities in society, their access to and control over resources, including information, and their decision-making power. This can have a dramatic effect on women and men's health attitudes and behaviours, on their roles in relation to health and healthcare, and on health needs.

Gender roles have a direct impact on health. For example, women bear a disproportionate burden of care for children and elderly relatives. Care work is generally associated with the "woman's" role and is largely undervalued. This burden of care often contributes to significant health problems.

Men are often socialised to value risk-taking behaviours and are less likely to seek help and support. This leads to unhealthy lifestyles and late access to health services.

The differing ways in which men and women need to be approached with regard to health information, promotion, prevention, and rehabilitation are often a function of the implications of them being male or female in society rather than their actual biological make up.

Why is gender important

- Men and women's biological susceptibility to disease and response to treatment can be different (Wiseman & Pardue 2001). Symptoms can vary according to sex as can responses to medicines (Klinge 2008). Historically, women have often been under represented as subject in scientific studies resulting in them being treated at times with medicines not adequately tested in women.
- The differing ways in which men and women need to be approached with health information, promotion, prevention, and rehabilitation are often a function of the implications of them being male or female in society rather of their biological make up.
- Gender labelling of non sex-specific diseases can lead to under diagnosis and incorrect treatment, but also to the under-representation of patients of one gender in related projects.
 - Cardiovascular disease is a major killer for men under 65 and often labelled as a male disease. Most studies have been carried out on men. Female symptoms can be different and are often not diagnosed properly yet it is the number one killer for women overall (Lockyer 2008).
 - Osteoporosis is considered as a female only disease. However 1 in 5 men will develop the conditions many of whom will be misdiagnosed (Geusens & Dinant 2007).
 - Other conditions with adverse gender bias in girls/women include Attention Deficit and Hyperactivity Disorder (ADHD) and lung cancer. In men/boys these include depression and eating disorders (Branney & White 2008).

Some benefits for patients of gender considerations in patient involvement

- The recognition that men and women are not just biological entities and that their health needs must be also recognised in terms of their socialisation as individuals.
- Gender sensitive recruitment and involvement of both women and men help avoid discrimination and ensure more equitable outcomes.
- Appropriate representation of men and women in health matters that affect them.



How to: Checklist for project co-ordinators

The following is a checklist for project co-ordinators to insure that gender is considered in relation to patient involvement in health projects:

- Have men and women been involved at all stages of project development and implementation?
- Has the project considered that its findings and outcomes may impact end users differently depending on their gender? Aligning the mix of male and female patients with expected project outcomes is more likely to reflect the needs of all patients male and female.
- Is there equal participation of males and females among patients involved? Unless there is evidence to the contrary, both men and women should be equally included.
- Data used and collected by the project should be sex-disaggregated so as to give a clear picture of the respective health needs of women and men.

Suggested reading

- Branney, P, White, AK (2008) Big boys don't cry: men and depression. *Advances in Psychiatric Treatment* 14: 256–262
- Catherine Vidal, Neurobiologist, Institut Pasteur, Paris, France, 'Brain, sex and ideology' in Talking Life to both Sexes, European Commission conference report, sec 1:9, February 2006
- European Commission Directorate-General for Research, Biotechnology, Agriculture and Food, Talking Life Sciences To Both Sexes, A Workshop on Research Communication and Gender, Conference Report, 9 February 2006.
- Geusens, P, Dinant, G (2007) Integrating a gender dimension into osteoporosis and fracture risk research. *Gender Medicine* 4 (supp B) S147-161
- John Oliffe and Lawrence Mroz; Men interviewing men about health and illness: ten lessons learned; *Journal of Men's Health* Vol. 2, No. 2, pp. 257–260, June 2005
- Lesley Lockyer (2008) Women's interpretation of cardiac symptoms. *European Journal of Cardiovascular Nursing* 7(3): 161-162)

- Klinge, I (2008) Gender perspectives in European Research. *Pharmacological Research* doi:10.1016/j.phrs.2008.08.011
- Wizemann, T.M. and Pardue M.-L. (2001) Exploring the biological contributions to human health: does sex matter? Washington, D.C.: Institute of Medicine.

EPF DIRECTORY OF EUROPEAN AND NATIONAL PATIENT ORGANISATIONS

It is available at EPF's website at www.eu-patient.eu/projects/valueplus/directory

OVERVIEW OF PATIENT RIGHTS IN EU MEMBER STATES

It is available at EPF's website at www.eu-patient.eu/projects/valueplus/resources/attached_documents/overview-of-patients-rights-in-the-member-states.pdf

IS THIS THE RIGHT PROJECT FOR OUR ORGANISATION? ANALYSIS OF STRENGTHS WEAKNESSES OPPORTUNITIES THREATS

A tool for use by patient organisations when considering a project.

Is this the right project for our organisation? Analysis of Strengths Weaknesses Opportunities Threats

STRENGTHS	WEAKNESSES
OPPORTUNITIES	THREATS

This can be done as a group activity, to identify the important issues when deciding on a project. The groups can consist of Board Members, paid staff, volunteers, and members of the organisation.

METHOD

1. The idea for the project is described to the whole group. Everyone helps to identify the **strengths** and the **weaknesses** of the idea, without going into detail. Record these on two flipcharts.

These questions may help you:

- **AIMS** How well does the project idea fit with the aims of our organisation?
 - **STRATEGY** How well does the project idea fit with the strategy for our organisation?
 - **RELEVANCE** How important are the expected project results for our patients?
 - **SKILLS** Do we have the skills for this project?
 - **CAPACITY** Do we have the capacity (people, time, equipment, matched funding) for this project?
 - **PARTNERS** How well does our organisation fit with the proposed project partners?
2. Discuss the **opportunities** and **threats** presented by the strengths and weaknesses you have identified, and record them on a flipchart. Depending on numbers of people present, you may split into smaller groups, each taking some of the topics.

Example: Perhaps you identified lack of a particular skill as a weakness. If good quality, cheap training is easily available, this could be an opportunity to improve skills in your organisation. If training is hard to find and is expensive, this could be a threat to the quality of the project.

These questions may also help you:

- **IMPACT** How will doing this project affect the other services we offer to our members during the project, and after it finishes?
- **VISIBILITY** How will this project affect the way other organisations, and the public, see our organisation?
- **WORKING WITH PARTNERS** What are the possible advantages or disadvantages of working with the proposed partners?
- **RESULTS & OUTCOMES** What does our organisation really want from taking part in the project? Does it fit with the possible project outcomes?

If you have split into smaller groups, come together and share your results.

By working through this [SWOT Analysis](#) in your organisation, you may reach a consensus decision on these questions:

- Does your organisation want to take part in the project?
- What changes are needed to the project plan before your organisation can take part?
- What changes are needed within your organisation before you can take part?
- Which areas of the project plan are the most important for patients to be involved?
- What support might your organisation need, and where might it come from?
- What does your organisation expect to gain from the project?
- What will your organisation do to avoid the possible threats identified?

You have also identified the hopes and expectations of everyone in the organisation, and discussed whether these can be achieved from the project. This forms a basis for evaluating your organisation's involvement in the project later.

VALUE+ CAPACITY AND SKILLS FOR AN EC PROJECT CHECKLIST

This checklist is intended to help organisations check whether they have the time and skills within their organisation, or within a group of organisations coming together in a project, to carry the project through. It should be used together with the 'Building capacity and skills for an EC project' description in the toolkit.



The proposal stage

Topic	Estimated requirements	Already available within organisation	Possibly available from
Preparing the proposal			
Costing the proposal			
Additional funding			
Finding/liaising with potential partners			
Presenting proposal and negotiating with funders			
Equipment and technology			

Running the project

Topic	Estimated requirements	Already available within organisation	Possibly available from
Financial management			
Staff/volunteer management and supervision			
Staff/volunteer training			
Communication with partners			
Communication with patients			
Reporting			
Specific project activity 1 – skills, knowledge, time			
Specific project activity 2 – skills, knowledge, time			
Disseminating project results			
Lobbying			

VALUE+ INVOLVEMENT OPPORTUNITY CHECKLIST

A checklist of the information to include when describing an involvement opportunity for use with an individual patient or patient representative. The information can be given in writing or during an interview. Make sure the examples are the right ones for your organisation.

Topic	Content	Written information	Interview
The Organisation	Description of the organisation offering the opportunity: their aims, membership, background including previous projects, funding		
	Details of contact person		
The Project	Description and aims of the project		
	Easy-to-read project information sheet with funding, partners, expected outcomes, and so on		
	Overview of how patients will be involved in the project, how many in each country		
The Task	Description of the specific task, relating it to the overview of patient involvement in the project		
	Description of how taking part in the project could affect the patient's treatment (if this applies)		
	Dates, venue, other practical details of the task		
	Time and other resources required		
	Support available (including training, payment, expenses, etc) for patients agreeing to do the task		
	A person specification – skills, knowledge, attitudes, experience needed for the task – don't make it too scary!		
	Establish what the project expects if the patient accepts the opportunity, eg. references, accepting supervision, attending training, liaising with other patients to represent their views, confidentiality		
The Agreement	Explore what the patient expects from the project, and feedback on whether the project can meet these expectations		
	Description and times of what the organisation will do next, if the patient is still interested		
	Description and times of what the patient needs to do next, if they are still interested		
	Ask whether the patient wishes to join the project mailing list for further information or opportunities		



It is good practice to give full information about an involvement opportunity to any patient and patient representative who may be considering getting involved. This will enable them to come to an informed decision whether to be involved on this occasion.

It is particularly important to establish what the project wants from involving a patient, and what the patient wants from being involved. Can these expectations be met?

The information may of course be given during a personal interview, when the patient can explore these issues with the patient organisation or other project partner. This should be backed up by written information.

Some tips:

- Use clear, simple language
- The atmosphere during an interview is very important. The patient must feel free to say what they really think
- The person specification should not scare people away. The person from the patient organisation must be prepared to explain the task and encourage patients to understand how their experience fits the task
- The interviewer and patient should also discuss how taking part in the project could affect the patient's treatment, and confidentiality issues.

SHORT INVOLVEMENT OPPORTUNITY INFORMATION SHEET

This is an example from Value+.

PROMOTING PATIENTS' INVOLVEMENT IN EC SUPPORTED HEALTH-RELATED PROJECTS – VALUE+

Value+ Toolkit for Patient Organisations Focus Group Berlin, 30th June 2009

The Project

Value+ is a two-year project funded by the EC Public Health Programme, to research patient involvement in EC-supported health-related projects. It aims to provide support both for patient organisations and for project co-ordinators on best practice in involving patients, through a Toolkit for patient organisations and a Handbook for project co-ordinators.

For more information, please see project information sheet or visit the website: www.eu-patient.eu/projects/valueplus/index.php

Job Description

The Value+ Toolkit for patient organisations is currently under development. We invite input from individual patients/patient representatives in patient organisations in two ways:

- By commenting on materials sent by email, during the drafting of the Toolkit
- By participating personally in a focus group in Berlin on 30th June 2009. The focus group will examine the draft toolkit and suggest improvements. It will also provide feedback on indicators for meaningful patient involvement.

Person Specification

- **Knowledge**
Substantial experience of patient involvement in national or European projects from a patient organisation perspective
- **Skills**
Ability to read documents in English
Ability to discuss patient involvement issues in English
- **Attitudes**
A commitment to supporting patient involvement, which patients themselves experience as high quality
- **Resources needed**
Access to email.

Practical Details

- **Time required**
We hope that you are interested in being involved in this task. We expect that some people not able to attend the focus group would still be interested in commenting by email. We expect that others will attend the group but not be able to give much more time beforehand. And we hope some people will do both!

Commenting by email: The draft table of contents will be ready soon. Please let me know if you are interested in seeing it. You then have an opportunity to make suggestions, and to identify the topics and sections you would most like to see when they are drafted. You choose how much you ask to see, how much you comment, and how much time you spend before the focus group itself!

The focus group will take place from 10am to 4.30 pm on 30th June, in Berlin. Some materials will be sent out the previous week, including the table of contents if you have not already asked to see it. Participants should allow time to read them and think about the issues before the group.

- **Payment**

Unfortunately Value+ is unable to make a payment for patient involvement in this task.

- **Expenses**

Value+ will pay travelling expenses to Berlin (up to €300), hotel costs for 29th and 30th June, and meals for those two days. We would prefer participants to book their own travel tickets if that is at all possible (but we can help if it isn't). Please keep the original tickets and receipts for all expenses. The European Patients Forum (EPF) will then reimburse the money.

Contact for expenses claims:

Name, address, telephone, email, website

- **Hotel booking**

Details of the hotel, meeting room, and local travel will be sent to you before the focus group. If you have any special requirements, either at the hotel or during the meeting, please tell us when you let us know you will be attending.

Contact for toolkit and focus group:

Name, telephone, email



GANTT CHART

Gantt Chart Value+ Period 2008-2009

- = Milestone
 ■ = Beginning and end of task/activity ■ = Duration

ACTIVITIES	FEB ⁵	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	JAN	FEB	RESPONSIBILITY
WP1 COORDINATION														
1.1 SG Meeting 1	●													EPF
1.1.1 Memorandum of Understanding	■	■												ALL
1.1.2 Conceptual framework WP4 (methodology, indicators)	■	■												ALL
1.1.3 Prepare draft ToR for evaluator	■													ALL
1.1.4 Discuss project logo and website	■	■												ALL
1.1.5 Prepare overall and individual Implementation Plan	■	■												ALL
1.2 SG Meeting 2						●								EPF
1.2.1 VALUE+ Briefing Note, Questions and Answers Note and PowerPoint presentation				■	●									EPF
1.3 SG Meeting 3														EPF
1.3.1 Discuss 6-8 show-case examples of patient involvement														ALL
1.4 Prepare interim report														EPF
1.4.1 6-month report from partners							■						■	Partners
1.4.2 Annual report from partners														Partners
WP2 DISSEMINATION OF RESULTS														
2.1 Develop a project logo		■	●											EPF
2.2 Develop website section		■	■	●										EPF
2.3 Dissemination event in Vilnius							■	■	■	■			●	EPF, SPC
WP3 EVALUATION														
3.1 Call for an external evaluator		■	●											EPF
3.2 Evaluator to prepare evaluation plan			■	●										Evaluator, EPF
3.3 Evaluator to prepare reports for SG meetings													■	Evaluator
WP4 ANALYSIS PATIENTS INVOLVEMENT IN EU HEALTH PROJECTS														
4.1 Exploring web pages of various European Commission DGs		■	■	■	■									ALL
4.2 Literature review		■	■	■	■	■	■	■	■	■				FEP
4.3 Interviews with project leaders and patients							■	■	■	■	■	■	■	ALL
4.3.1 Draft interview guides					■									
4.4 Survey with EPF members		■	■	■	■	■	■	●						EPF
4.4.1 Design survey questionnaire		■	■											EPF, Empirica
4.5 Outline 6-8 show-case examples of patient involvement														EMP EPF
4.5.1 Defining criteria for selecting the show-case examples					■									
4.6 Focus Groups meeting London							■	■	■					ENUSP
4.6.1 Define a framework for focus groups					■	■	■							
4.7 Create VALUE+ Database on projects							■	■	■	■	■	■	■	EPF
WP5 SUPPORT PATIENTS ORGANISATIONS INVOLVEMENT IN HEALTH PROJECTS														
5.1 Identify projects					■									EPF, FEP, ENUSP
5.2 Define the work methodology					■									EPF, FEP, ENUSP
5.3 Reach formal agreement with project leaders								■	■					EPF, FEP, ENUSP
5.4 Interviews with project coordinators and representatives of patient orgs.													■	EPF, FEP, ENUSP

5 Starting month of the action as per the contract.

CRITICAL PATH EXAMPLE FROM VALUE+

This is based on the task of holding a focus group. To be useful the 'Who' column must be completed.

■ = Indicate deadlines for task/activities

Focus group	Who	JUL	AUG	SEP	OCT
Select and contact potential projects and participants				By Fri 12th	
Identify suitable projects who may send a participant		Mon 14th			
Prepare information letter about the focus group, and contact projects by email/letter		Mon 21st			
Follow-up by phone		Fri 25th			
Finalise invitation letter, send to identified participants			Fri 8th		
Follow-up on replies			Fri 22nd		
For all potential participants, check additional support needs				Fri 12th	
Detailed plan for the group				By Fri 26th	
Consult project partners about topics and finalise the topics			Fri 29th		
Identify and book hotel accommodation for participants and facilitators			Fri 22nd		
Identify/book meeting room			Fri 22nd		
Send hotel and travel details to participants, with topic guide				Fri 19th	
Prepare detailed plan for the day, consult partners				Fri 19th	
Finalise day plan				Fri 26th	
Hold Focus Group					Fri 10th
Book co-facilitator/scribe			Fri 29th		
Brief co-facilitator/scribe				Mon 29th	
Ensure equipment required is available				Fri 26th	
Prepare presentations, handouts, etc				Tue 7th	
Write report					By Mon 20th
Consult partners re report headings			Fri 25th		
Write up report					Week 13-17th



VALUE+ DATABASE OF EC- SUPPORTED HEALTH PROJECTS WITH PATIENT INVOLVEMENT

The database is accessible at www.eu-patient.eu/projects/valueplus/database

RISK LOG FOR THE IMPLEMENTATION OF AN EU PROJECT

You can add as many risks as you think likely for your project. The risks can refer to management, partnerships, activities or relationship with the EC.

Risk nr.	Task	Risk	Probability	Impact	Mitigation plan
R1	Operational Co-ordination	Discrepancy between planned and reality	Low	Medium	Resources and tasks will be reallocated to readjust delays and ensure the respect of the project schedule
R2	Financial and Administrative Co-ordination	Delays in the preparation of periodical reports and cost statements	Low	Medium	Partners will receive clear guidelines on the timeline and modalities for reporting
R3	Creation of project website	The website is rarely visited	Low	Medium	External expertise will be sought to create an attractive and accessible website
R4	Survey with on-line questionnaire	Not many people will reply to the questionnaire	Medium	Medium	The questions and technical functioning will be clear and simple There will be interviews and focus groups to build on questionnaires' results
R5	Focus groups with patients	The meetings fails to attract the right profile of patients	Low	Medium	The recruitment will be started well ahead of meeting and all partners will contribute
R5	Organisation of final project conference	The event fails to attract the right quality and/or right number of delegates	Low	Medium	Necessary preparatory work will be done

6.4 EXAMPLES AND TOOLS FROM OTHER ORGANISATIONS

In this section we include some tools developed by organisations to support their own work with patients. These tools fit their own needs and reflect their own priorities. We are grateful that the organisations have allowed us to use these as examples, and thank them for their permission to reproduce this information here.

VOLUNTEER'S JOB DESCRIPTION

This is an example of a volunteer's job description from an NGO in the UK. The original included a header with the date the description had been agreed by the Board

VOLUNTEER ADVOCACY WORKER

Job Summary

To respond to enquiries on mental health and related topics from people experiencing mental distress and other members of the public, and to help maintain the systems that support this work.

Location:

Responsible for:

Responsible to: Named Co-ordinator.

Salary Scale: Volunteer

Hours: Negotiable

Duration of Contract: N/a

Specific Responsibilities

1. To provide an advocacy service to people in the agreed client group.
2. To work as a member of a team of volunteer advocates on visits to areas where a service is provided, attend 'de-brief sessions' and describe or hand over any issues arising.
3. With Co-ordinators, to maintain the routine administrative systems that support the work of the organisation's Services.
4. To research topics where necessary either to help individual clients or to develop resources for staff and volunteers.
5. To work in an appropriate and mutually supportive manner with other volunteers and paid staff members.
6. To work to the Operational Guidance for the Advocacy Service, and maintain a good level of familiarity with this guidance.
7. To work with vulnerable adults, and consequently to disclose any criminal convictions so that the organisation may be satisfied that you do not become a risk to clients (see procedure for Criminal Records check).

General Responsibilities of All Staff

1. To ensure that the service promotes people's rights, assists mental health service users in speaking for themselves, and works against discrimination and disadvantage.
2. To ensure the services of the organisation are attractive and relevant to Black and minority ethnic communities, women and other groups whose needs have not been historically met, demonstrating a commitment to equality of opportunity and outcome.
3. To provide a flexible and responsive service which encourages people to participate in its running and creative development.
4. To work within the policies of the organisation and ensure they are put into practice.
5. To assist with the development of policies and procedures relevant to the individual's role.
6. To liaise with statutory and voluntary sector professionals and other local and national organisations, users' and carers' groups and projects where necessary to ensure an appropriate service.
7. To encourage other groups to use the organisation in a variety of ways.
8. To identify issues of general concern arising from services' work.
9. To enable users of mental health services to participate in the development of new initiatives: to develop meaningful forms of feedback and influence change in the organisation.
10. To be administratively self-servicing.
11. To attend staff meetings and regular supervision sessions as required.
12. To carry out such other functions as may be necessary for the successful running of the organisation.



GUIDELINES ON MAKING PRESENTATIONS

This document contains a brief on the content for a specific presentation, and general guidance on making a presentation. The document was written by Jo Lucas for the Centre for Excellence in Interdisciplinary Mental Health (CEIMH), University of Birmingham, UK

CEIMH INTERNATIONAL USER RESEARCH SEMINAR 2009

Brief for people making presentations

The theme for this seminar is 'What have we learnt about involving users in research and what can be done to overcome the obstacles' so make sure you keep this in mind for your presentations.

Time

- Each presentation can last a maximum of 15 minutes with 15 minutes for questions and discussion.
- This time limit will be strictly adhered to.
- Each presentation will be chaired by Jo or someone else who will have a clear brief to ensure that each one does not last more than the allotted time.
- If you are not used to speaking, practice before you come, remember to speak slowly and time yourself. You are very likely to prepare far more than you will have time for so cut the content down to what you really want to say.

Content

Remember to agree a title with Jo that can be inserted in the programme so others know what to expect and what to prepare for.

The focus of each presentation is the research that you or your team have been doing.

Please focus on:

- Either the results of your research in terms of how users were involved in the outcomes
Or
- The process of involving users and professionals and what you learnt from that.

Don't go into every detail, think about what the key lessons or outcomes are and what will be interesting for others to know, in the time allotted.

If you can, prepare some handouts or some back up materials so the audience have something to look at other than you – always a good tip if you are feeling nervous.

PowerPoint or avoiding “Death-by-PowerPoint”

If you want to use PowerPoint – or something similar – that's fine. Remember to bring it on a stick so it can be transferred to a computer in CEIMH.

Do remember that PowerPoint is a visual aid, it is NOT a substitute for the text of your presentation.

The point is that it gives you clue as to what you want to say next, keeps you to the structure you have designed – so you don't go wandering off onto what appear to be interesting ideas at the time, and it gives people something to look at in addition to what you are saying, so use pictures and other visuals when you can.

Your presentation will be most effective if you use it as a reminder of what you want to say- don't put the whole text on each slide just a few key words and put your full text on the notes that go with it and that you can see on the screen but the audience cant.

The MOST BORING PRESENTATIONS are when people simply read out what is on the PowerPoint slide and in these situations they almost always put loads of words on each slide and the audience promptly falls asleep. Why should they bother to listen when they can read it all there anyway? Also as reading is quicker than speaking the audience will always be ahead of you.

The rule of thumb is no more than six items on one page, and use visuals-pictures diagrams etc – when you can, and speak about what is on the slide.

Reading your presentation out

If you are not used to making presentations you may want to write it out beforehand and then read it out to us.

The things to remember are

- Speaking is slower than reading so it will take longer to speak it than to read it to yourself.
- The structure of spoken English is different to written English. So when you are writing it, speak it aloud to yourself (either in your mind or if someone is willing to listen to it) to see if it sounds all right to you. This also means you don't have to worry too much about the English grammar – the sense is what is important.

- Put it onto something that you will be able to look at easily. Many people often put notes on plain post-cards, as being a bit more rigid than paper they are easier to hold and look at while you are standing up. (My first ever speech I carefully wrote out on ordinary paper. I then discovered there was a microphone in the hall and all people could hear was the rustling of those papers as my hands shook with nerves!).
- Remember to speak slowly and clearly and to breathe while you are speaking – otherwise we tend to speak faster and faster and our voice gets more and more high pitched! Breathing is also likely to take the shakiness induced by nerves out of your voice.
- Remember to look at the audience if you can. Try and look around the room and if someone looks as if they are paying attention and are interested pretend you are talking to just to them. This means you can ignore the people who might look as if they are dreaming, those who might make you feel even more nervous.
- Decide beforehand and let the chair know – are you happy to take questions as you go along or do you just want to get the presentation over with without any interruptions. Either is fine, but the chair and the audience need to know.

Speaking tips

- Speak slowly and clearly don't rush it
- Remember to breathe while you are speaking
- Don't try and tell us everything, only those key elements that you think are important
- Look at your audience
- If you feel happier walking about do so, if you feel better standing in one place behind a stand or whatever, do that
- Decide beforehand if you are going to write out your speech word for word and read it out or if you feel happier just preparing a few notes or cues to remind you that you can elaborate as you make the presentation
- Use short sentences.

I think it was Kennedy's speech writer or someone similar, who said once 'The essence of a good speech is that you decide where you are going to go, what you are trying to say, before you start out and you make sure that you have got there by the end of the speech'.

I look forward to hearing and seeing all your presentations.

Jo Lucas
July 2009



'HOW DID WE DO WHEN WE INVOLVED YOU!!'

This evaluation was designed by grassroots patients from a UK health agency's user group to give feedback on their experiences of being involved.

SERVICE USER REFERENCE PANEL

Feedback Form for Involvement

How did we do when we involved you!

You were recently involved in:

That took place at:

On:

"What good involvement feels like to service users and carers"

- When I am fully involved I feel happy, excited, interested and important
- When I am fully involved I feel informed and understand what is going on
- When I am fully involved I feel powerful enough to change things
- When I am fully involved I feel like a respected and equal citizen with rights

Please tell us what you think by answering the following questions

Please tick the faces that tell us what you think and write any other things you want to tell us.

BEING INFORMED

1. Were you told enough for you to be able to take part?



Yes



No



Sometimes

2. Did we keep you informed and tell you what was going on?



Yes



No



Sometimes

3. Did you understand what we said?



Yes



No



Sometimes

4. Were you told who to ask to get more information?



Yes



No



Sometimes

How could we have informed you more?

LISTENING TO YOU

1. Whilst you were taking part did we treat you with courtesy and respect?



Yes



No



Sometimes

2. Did you feel your views and opinions were listened too?



Yes



No



Sometimes

3. Did you feel your views and opinions were taken seriously?



Yes



No



Sometimes

How could we have listened to you better?

TAKING PART

1. Were you clear about why you were taking part?



Yes



No



Sometimes

2. Did we tell you what you could change?



Yes



No



Sometimes

3. Did we tell you what you could not change?



Yes



No



Sometimes

4. Did you feel able to take part?



Yes



No



Sometimes

How could we have involved you more?



WHAT DIFFERENCE HAS YOUR INVOLVEMENT MADE?

1. Did you feel you were able to influence the decisions that were made?



Yes



No



Not Sure

2. Did you get a chance to say what you wanted to say?



Yes



No



Not Sure

3. Did anything happen as a result of you taking part?



Yes



No



Not Sure

4. Did we tell you what, if anything, has happened?



Yes



No



Not Sure

5. Overall, did you feel it was worthwhile taking part?



Yes



No



Not Sure

Is there anything else you want to tell us?

Would you want to be involved with us again?

Have you recognised any training needs?
(please use an additional sheet if necessary)

THANK YOU

Please return to:
(Address removed)
or leave at the meeting in the plain envelope provided. Your comments are anonymous.

'CHECKLIST FOR RESEARCHERS WISHING TO RECRUIT PARTICIPANTS TO THEIR RESEARCH OPPORTUNITIES THROUGH ASTHMA UK'

This is an application form for researchers requesting Asthma UK to help them recruit research participants.

Checklist for researchers wishing to recruit participants to their research opportunities through Asthma UK



The attached application form is designed to assist Asthma UK in making decisions about which research opportunities we are able to inform our database of Research and Policy volunteers about. We may also be able to feature opportunities in our magazine, newsletters, electronic media and other correspondence, to help researchers recruit people affected by asthma to their research studies.

The following guidelines detail our criteria and the information we require; they also detail the obligations you have to our volunteers.

Research opportunity criteria

Eligibility for recruitment

1. Asthma UK welcomes applications from UK researchers wishing to recruit UK-based participants into their research activity. In your application you will need to show:
 - the benefit of your research to people living with asthma in the UK
 - where the research will be conducted
 - who will conduct the research
 - how you will communicate with your participants
 - the evidence of your eligibility to conduct research in the UK
2. Applications must clearly state any commercial support or links to research studies. Asthma UK will not accept any applications from researchers who have funding support from the tobacco industry.

Peer review and ethical approval for research study recruitment

1. For researchers looking to recruit participants to their research study, the study must have been peer-reviewed and be funded by a recognised organisation, for example:
 - Asthma UK
 - Other charities or not-for-profit organisations with independent peer-review systems (eg the Wellcome Trust)
 - Research Councils
 - NHS
 - Department of Health
 - Recognised institutes of education (such as universities)
 - Other reputable non-commercial or commercial institutions who have submitted their research to peer-review and ethical approval.



Research opportunity criteria continued

2. If the research study relates to equipment, the research must have been independently reviewed and approved by the MHRA for its use and trial in the UK
3. The research study must have been approved by a recognised or authorised Local or Multi-centre Ethics Committee (LREC or MREC)
4. As is required by law, if the research study is a clinical trial, this must have approval from the MHRA, and follow-up appointments must be provided for participants following the completion of the trial

Financial information

1. Annual accounts of the funding and/or research organisation must be readily available

Please note:

You will be asked to provide copies of all documentation relating to the peer-review process, ethics approval licence numbers, insurance cover and financial accounts

Relevance of the research to Asthma UK's aims and objectives

1. The research opportunity must relate to Asthma UK's vision: 'Control over asthma today, freedom from asthma tomorrow'. This must be clearly demonstrated in the purpose and outline of the research opportunity (Section 4)
2. The potential benefit and risk to the individual participants must be clearly defined in the purpose and outline of the research opportunity
3. If the opportunity is to participate in a research study and the research replicates a previous study, please give reasons

Obligations to research participants

Insurance cover

1. Insurance cover for study participants must be disclosed and clearly explained

Costs

2. All out of pocket expenses, including travel, subsistence and overnight accommodation where applicable, must be reimbursed
3. Any remuneration should be made clear from the start of the project and should follow British Medical Association guidelines

Please be aware that there are two key factors relating to costs that may influence the participant's choice to join a research trial:

- Participation in your study may have an impact on participants' personal insurance policies, and they are encouraged to check before joining.
- Reimbursements for participating in your research could affect the participant's social security benefits. If they receive means tested benefits, it is advisable that they contact the Department of Work and Pensions to make sure that their benefit entitlement will not be affected

Research opportunity criteria continued

Information

4. The research organisation and any individuals or organisations working on their behalf must adhere to all relevant guidelines relating to participant consent, confidentiality and data protection
5. As well as any information that you are required to give participants as part of the ethical approval for your research, the following information must be given to participants in a format and language that is appropriate to their needs:

Before the opportunity/study

- A lay summary of the research study must be given in clear, jargon-free language that is appropriate to the needs of the participants. This should include information about research aims and proposed timescales
- A brief summary of the potential benefits of participating in the research study for the individual and more broadly for people living with asthma
- Clear information about the potential risks of participating in the research opportunity
- Clear information about reimbursement of expenses and any remuneration
- If the opportunity is to take part in a research study, insurance cover for the study must be disclosed
- The name and contact details for a research representative should be given to participants in case they have comments or concerns while participating in the opportunity

After the opportunity/ study

- A summary of the outcomes in easy-to-read, jargon-free language, appropriate to the needs of the participants. For research studies, this should be given once the results of the research are publicly available
- If the research study is a drug trial, participants should be informed of which drug they have been taking for the research study and at what dosage. They should also be given clear information about whether or not they are likely to be able to access this drug after the research study has been completed and once the results of the research are publicly available

Dissemination of research findings ■

1. Asthma UK expects to be given advance notice of any media releases or publications arising from the research opportunity
2. Where appropriate, researchers are encouraged to post research study findings on their institution's website or in printed or electronic media that is readily accessible to the UK public



THIS IS AN APPLICATION FORM FOR RESEARCHERS REQUESTING ASTHMA UK TO HELP THEM RECRUIT RESEARCH PARTICIPANTS.

Application form for recruitment of research participants through Asthma UK



Compliance with the Data Protection Act 1998

In accordance with the Data Protection Act 1998, the personal data provided on this form will be processed by Asthma UK, and may be held on computerised databases and/or manual files.

Section 1: Contact information

Please provide the following information for each investigator involved in this research opportunity

Contact details of principal applicant:

Title		
Name		
Job title		
Address		
		Post code:
Telephone:	Fax:	Email:
What is your role in the research opportunity?		

Co-applicant 1:

Title:	Forename:	Surname:
Job Title & Institution:		
Role in research opportunity:		

Co-applicant 2:

Title:	Forename:	Surname:
Job Title & Institution:		
Role in research opportunity:		

Section 2: Funding information	
Research sponsor(s)	
If the research is being funded by a pharmaceutical company, please state proportion of funding:	
Address	
Telephone and email	
Research funder(s)	
Address	
Telephone and email	

Section 3: Licences, ethical approval and insurance information	
Has the research study been peer-reviewed?	Yes / No/ N/A
If yes, please advise how this was done and, where possible, the individuals involved	
Does this research require any approval from any Ethics body? (please delete as appropriate)	
Yes: I have attached a copy of the Ethics Approval documentation	
Yes: I have not yet received Ethics Approval	
No: I do not require Ethics Approval	
Ethical committee approving the study:	
Ethical approval licence number:	
What insurance cover is in place for the study for the research participants?	
Are the annual accounts of the funding organisation readily available?	Yes / No
If so, where can these be located?	



Section 4: The research opportunity

Purpose of the opportunity

In no more than 500 words please give a summary of the proposed activity including the background to the work, aims, methodology and timescale. Applicants should also demonstrate how the proposed research fits with Asthma UK's aims and objectives.

If you are conducting research on behalf of a Third Party please include information about this organisation.

Brief lay summary

In no more than 100 words please provide a lay summary of the proposed opportunity that can be used to recruit participants. This should be suitable for Asthma UK publications and website if applicable.

Does this research replicate an existing study?

Yes / No

If yes, please give reasons

What are the outcome measures and their relevance to asthma?

Section 5: The research participants	
What are the eligibility criteria for participating in this research opportunity?	
Where will the opportunity take place?	
How many people do you hope to recruit to the opportunity?	
What is the closing date for recruitment?	
Will each participant's GP be notified about their involvement in this research study?	Yes / No / N/A
What steps will be taken to ensure that information about participants is stored and used in compliance with the provisions outlined in the Data Protection Act 1998?	
Will all out-of-pocket expenses be reimbursed to all research opportunity participants?	Yes / No
Will you provide the information to participants as detailed in the 'obligations to participants' section of the guidelines accompanying this form?	Yes / No
If required, can you provide information appropriate to the needs of the participant (including foreign languages and Braille)?	Yes / No
<ul style="list-style-type: none"> ▪ If this material or a draft is already available, please enclose a copy with your application 	



Section 6: Dissemination of research findings		
I/we understand that allowing recruitment of participants through Asthma UK does not imply that Asthma UK is in any way the sponsor of the research and is, therefore, not liable for any claims concerning negligence, harm or oversight that might arise during the course of the research		Yes / No
I/we agree to provide Asthma UK with advance notice of any media releases or publications or publications arising from the research		Yes / No
I/we agree to provide Asthma UK with a summary report of the findings once they are made publicly available		Yes / No
I/we agree to provide all research participants with a summary of the findings of the research project in jargon-free language appropriate to their needs?		Yes / No
I/we agree to make every attempt to publish the findings of the research regardless of a positive or negative outcome		Yes / No
Applicant's name	Signature	Date

Thank you for taking the time to complete this form thoroughly.

Please return to:

Malayka Rahman, Research Officer

Email: mrahman@asthma.org.uk

Asthma UK, Summit House, 70 Wilson Street, London EC2A 2DB

Please note: Asthma UK have asked that anyone using their form in any way should contact them to let them know how it is being used.

THIS IS WHAT YOU NEED TO THINK ABOUT AS A PATIENT RESEARCH PARTNER

Guidance from the Swedish Forskningspartner project to the patients it has trained as research partners for projects.

PATIENT PARTICIPATION IN RESEARCH

This is what you need to think about as a patient research partner

Be certain to get as much information as you can about the project. Request the researchers to specify how they have planned your involvement

- What is their aim?
- How long will the project be going on?
- When and for how long will you participate?
- Approximately how many hours?
- Which meetings are you expected to participate in?
- Are there any contracts that you are expected to sign?
- What can you tell other people about the project?
- Who will be paying for expenses?
- Do you have a special person to contact on the research team?

Remember that it takes time to get started. Be patient!

Don't be afraid to ask!

If you have any problems, get in touch with the project leader in your organisation who is also your contact person.

Write in your notebook after every activity.

Visit the homepage and our forum where you can get in touch with the other patient research partners.

There is a glossary on the homepage.

Use the manual, there is a lot of information in it.

As a patient research partner you represent your organisation.

Don't forget that your knowledge about living with a chronic illness is unique and important.

Swedish Rheumatism Association
Caroline Åkerhielm, Project Leader
www.forskningspartner.se

WHAT YOU NEED TO THINK ABOUT WHEN ENGAGING A PATIENT RESEARCH PARTNER

Guidance from the Swedish Forskningspartner project to research projects which are including a trained patient research partner.

PATIENT PARTICIPATION IN RESEARCH

What you need to think about when working with a patient research partner

Be certain to give the patient research partner as much information as you can about the project. Specify what you have planned about their involvement

- How long will the project be going on?
- When and for how long will they participate?
- Approximately how many hours?
- Which meetings are they expected to participate in?
- A contract between the research team and the patient research partner can be a good thing.
- Make it clear who will be paying for expenses?
- Appoint a special contact person?

The patient organisations have their own contracts between them and the patient research partner.

There is also a person in each organisation responsible for the patient research partners.

Visit the homepage and our forum where you can get in touch with the other researchers.

Swedish Rheumatism Association
Caroline Åkerhielm, Project Leader
www.forskningspartner.se

VIDEO CLIP CHALLENGING STIGMA

This clip is from the Parkinson's Disease Society of Romania see www.eu-patient.eu/projects/valueplus/resources/attached_documents/ourdream.wmv



6.5 LITERATURE AND WEBSITES

In this section we list the websites where publications and resources described in the toolkit can be found. When reports or websites relating to the projects we have contacted during the Value+ are available on the internet, we list them in Section 6.2. Websites of other projects are included below.

Some websites contain many publications or a range of useful information, so we describe the websites in more detail.

In general, we have tried to signpost material which is available on the Internet, from websites that are updated. There are some useful publications which are available only in print.

In response to requests from some patient organisations, we include some information about best practice in clinical trials.

Here are the publications and websites, with the publication titles shown in bold, under the following topic sections:

- **Patient and service user involvement – best practice**
- **Patient and service user involvement in research**
- **Best practice in clinical trials**
- **Volunteering**
- **Governance of organisations**
- **Communication**
- **Anti-stigma campaigns**
- **The European Union**

Topic – Patient and service user involvement – Best practice

- The Service User Involvement Best Practice guide consists of video clips as well as written information. www.serviceuserinvolvement.co.uk
- **Involve** is a national advisory group in England which supports active public involvement in health services and health and social care research. Many of the guidelines in its publications section have been developed with patients and the public. The guidelines cover many topics: good practice, involvement in reviewing research proposals, involving young people in research, involving vulnerable and marginalised people are just a few. There are easy-read leaflets on public involvement. www.invo.org.uk/

- **Setting Standards for Youth Participation** by the International Planned Parenthood Association. www.ippf.org/en/Resources/Guides-toolkits/Setting+Standards+for+Youth+Participation.htm
- **Beyond the Usual Suspects: Developing diversity in involvement** – project funded by the UK Department of Health. www.shapingourlives.org.uk/dd2005.html
- **Guidelines for Patient Involvement** from the International Alliance of Patients' Organizations. www.patientsorganizations.org/showarticle.pl?id=591&n=962
- **A Guide to User-Focused Monitoring** – a guide to evaluating services, developed by service users (extract only – full publication available to purchase). www.scmh.org.uk/publications/guide_to_UFM.aspx

Topic – Patient and service user involvement in research

- **User Controlled Research: its Meanings and Potential** – Turner and Beresford. The full report and an easy-read version can be downloaded from the Commissioned Work section of the Involve website Publications section. www.invo.org.uk/Commissioned_Work.asp
- 'Handbook of Service User Involvement in Mental Health Research' edited by Jan Wallcraft, Beate Schrank, and Michaela Amering, published by Wiley-Blackwell ISBN 978-0-470-99795-6. Several mental health service users and survivors, as well as health professionals, have written chapters in this book. Only available in printed version.
- 'This is Survivor Research' edited by Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle and Diana Rose published by PCCS Books ISBN 978. Only available in printed version.

Topic – Best practice in clinical trials

- **The Eurordis Charter for Clinical Trials in Rare Diseases** developed by the European Organisation for Rare Diseases. www.eurordis.org/IMG/pdf/Charter_Clinical_Trials-Final.pdf

- The ongoing **RESPECT** project aims to identify the needs of children and their families in relation to clinical trial outcomes. This includes the needs of children who have participated or who might participate in clinical trials in Europe.
www.eu-patient.eu/projects/respect/project/purpose-outcomes.php
- The ongoing **Patient Partner** project aims to promote the role of patient organisations in the clinical trials context. Patient Partner is based on the belief that involving patient organisations as equal partners at all stages of clinical trials contributes to research that is better adjusted to the real needs of patients.
<http://patientpartner-europe.eu/>
- The **National Council for Voluntary Organisations** in the UK has an Advice and Support tab, that gives access to guides on being a Board Member, managing volunteers, and many other topics. It also has a section on 'Influencing the EU'.
www.ncvo-vol.org.uk/
<http://www.ncvo-vol.org.uk/influencingtheeu>
- The **European Patients' Forum** has run seminars on 'Strengthening Your Organisation'. Reports and presentations from these events are available as ISO or ZIP files the 'Conferences and Seminar Reports' Section reached through the Publications tab on the homepage.
www.eu-patient.eu/

Topic – Volunteering

- **Charter for Effective Volunteering** – Volunteering Ireland gave us permission to use their charter at the Berlin focus group. Some participants said their country did not have a culture of volunteering, and did not relate patient involvement to volunteering. The Charter appeared to give them new ideas. Volunteering Ireland has information about volunteering on its website in many languages, including on recruiting volunteers.
www.volunteeringireland.com/
- **Volunteering England** has information sheets and a Good Practice bank with tools from several different organisations. Click on the Managing volunteers tab on their home page.
www.volunteering.org.uk/
- **Legal Status of Volunteers – Country Reports** can be found through the Research and Publications tab from the The European Volunteer Centre/Centre Européen de Volontariat homepage. There is also information about the European Year of Volunteering.
www.cev.be

Topic – Governance of organisations

- The **Global Forum on NGO Governance** has a Resources tab on its homepage. Lists of publications available in different languages can be found by clicking on the language tab .
<http://ngoboards.org/>

Topic – Communication

- **How to Write Medical Information in Plain English** Click on the 'Free Guides' tab on the homepage of The Plain English Campaign for its guide to writing plain English, and guides to writing on medical and other specialist subjects in a way that ordinary people can understand.
www.plainenglish.co.uk/
- The World Wide Web Consortium (W3C) is revising its current guidance on how people with disabilities use the web. This address gives the latest guidance.
www.w3.org/WAI/intro/people-use-web

Topic – Anti-stigma campaigns

- The UK national mental health charity **MIND** is leading a programme to end discrimination on the grounds of mental ill-health.
www.time-to-change.org.uk/home/
- **MIND's** anti-discrimination information and training for employers.
www.mind.org.uk/workplace

Topic – European Union

The addresses given are for pages in English – other EU languages are also available through the Europa portal

- The main portal to the European Union's website, giving access to information in 23 European languages.
<http://europa.eu/>
- An introduction to EU funding.
http://ec.europa.eu/grants/introduction_en.htm



- Grants, Funds and programmes by EU policy. http://ec.europa.eu/grants/index_en.htm
- Commission representations, Parliament Information Offices, Your MEPs, Information Networks, EU Agencies in Your Country, listed by Member State. http://europa.eu/euinyourcountry/index_en.htm
- National contact points for the 7th Framework Programme. http://cordis.europa.eu/fp7/ncp_en.html
- National contact points for the Public Health Programme. http://ec.europa.eu/eahc/documents/list_NFPs.pdf
- The European Citizen Action Service supports European citizens to get their voices heard within the EC. www.ecas.org/

6.6 THE VALUE+ LITERATURE REVIEW

The Value+ Literature Review was carried out by the Spanish Patients' Forum, a partner in the Value+ project. It examined over 650 publications worldwide that related to patient and consumer involvement.

This toolkit includes a short summary of the Literature Review. The full Value+ literature review is available on www.eu-patient.eu/projects/valueplus/resources/attached_documents/valueplus-literature-review-on-patient-involvement.pdf

PATIENT INVOLVEMENT IN THE SCIENTIFIC LITERATURE: A REVIEW

EXECUTIVE SUMMARY

INTRODUCTION

A literature review is often carried out in projects to better understand issues and trends and to help setting the framework of a project. As part of the Value+ assessment of patient involvement in projects, a literature review was completed to have the bigger picture of the involvement of patients both at individual level as well through representative patient organisations in health policy, healthcare systems and service delivery, and of course projects.

Patient involvement is the focus of this review with a particular eye on "meaningful" involvement and also on the gender dimension of patient involvement. The result of this analysis determines the state of the art of research in the literature pertaining to this topic.

OBJECTIVES

The main objective for doing this work was to draw some guidance on how to frame the research to be done in Value+ mainly through a qualitative approach. The findings of the review would tell us which issues and problematic we should address in the questionnaire survey, the focus groups, workshops and interviews.

By checking the literature we wanted to find answers to the following questions:

- How is patient involvement in health perceived?
- Which are the main areas and mechanisms of patient involvement in health?
- To what degree do the diverse stakeholders accept patient involvement?
- To what degree do barriers inhibit patient involvement in health?
- What is the impact of patient involvement on the health policy making process?
- How does patient involvement vary at the national, European, and international levels?
- Which countries serve as models for patient involvement?
- Which recommendations have experts provided to improve patient involvement at the national, European, and international levels?

What we found out directly from current or completed EC-funded projects matched well with what we had learned from the literature.

METHODOLOGY

MEDLINE forms the basis of the literature research on patient involvement. Further relevant documentation has been obtained from the EU, WHO, OECD documentations, national health ministries, patient organisations, and patient-centered academic institutions. A total of 650 patient involvement and participation documents were analysed based on four categories of patient involvement: actors, health, action, and output.

CONCLUSIONS

Definitions and Concepts

- The term patient is often used interchangeably with others apparently similar such as: user, citizens, health users, service user, lay person, client, people, communities or the wider public. This ambiguity adds to the complexity of patient involvement because a term is associated to ways of seeing and portraying people and their relationships with the healthcare system

- A specific definition of patient is important because the definition determines the quality and effectiveness of the whole process of involvement from five points of views: “Who to involve (the representativeness), the reason for their involvement (the focus and nature of the involvement), their role and responsibilities (the level, comprehensiveness and depth of involvement and participation); how decisions will be made (democracy, transparency and accountability of involvement) and the evaluation of their involvement” (Pivik, 2002⁶; Tritter, 2006⁷; Boote, 2006⁸)
- While there is diversity across European and non-European countries about the manner to interpret and implement patient involvement into the healthcare system, there is still a common challenge concerning the concept of meaningful patient involvement
- The growing emphasis on patient involvement is linked to the emerging of concepts like patient-centred healthcare and patient empowerment. The first called for a new, more humanistic approach to healthcare that would take into account not only the disease but also the patient’s experience of it. The literature indicates that among the core principles of any patient-centred healthcare model, patient involvement and participation are always present despite the differences of models.

Patient involvement and democracy

- While patient involvement is considered as a right in matters of clinical and medical decisions making – and thus is included in patients’ rights legislations – it is rarely seen as such in other contexts, e.g. health policy making and therefore lacks proper regulation
- Countries with a greater focus on patient involvement are the same across time. The literature shows also that the countries producing the major number of publications on this topic are, at the same time, those with a longer tradition in democracy, patient rights and citizen’s participation.
- The increasing interest on patient involvement coincides in the time with the renaissance of public’s health policy debates on the redefinition of the concept of shared decision-making provoked by the appearance of a new term from the French healthcare system: the participatory democracy.

Shared decision making is one of the most recent and standardized models fostered by European and international healthcare research to denote patient involvement, but in a limited way of intervention: the clinical and medical encounter. It is for this reason that the main concern for the literature research still remains the difficulty to have a comprehensive and systematic approach to patient involvement in a broader context than the medical one that would include policy making.

The gender dimension of patient involvement

- An analysis of the gender dimension of patient involvement is clearly lacking
- Patient involvement and gender have in common the gap between theory and reality especially in decision-making bodies and processes.

Elements supporting meaningful patient involvement

- Despite the complexity of involvement, the literature shows a remarkable degree of convergence in the elements considered key for a successful involvement of patients:
 - Political and relevant stakeholders’ commitment to patient involvement
 - Development of a patient involvement agenda at health policy and research levels
 - Comprehensiveness of involvement so as to guarantee the integration of patients at all levels of the healthcare system (macro, meso and micro)
 - Adequacy of involvement to the patient-centered-dimensions of healthcare
 - Development and implementation of the involvement according to patients’ values, needs, preferences and expectations
 - Assessment of the quality, effectiveness and sustainability of patients involvement
 - Accountability on patient involvement by the healthcare systems at local, national and European levels.

6 Pivik J.R.; Practical strategies for facilitating meaningful citizen involvement in health planning. Ottawa: University of Ottawa, 2002.

7 Tritter J.Q.; McCallum, A. The snakes and ladders of user involvement: moving beyond Arnstein. Health Policy 2006;76:156-168.

8 Boote J.; Barber R.; Cooper, C. Principles and indicators of successful consumer involvement in NHS research: results of a Delphi study and subgroup analysis. Health Policy 2006; 75:280-297.



- The literature indicates three important concerns in relation to the realisation of patient involvement in a systematic way:
 - a) The opportunities offered by healthcare systems: despite the increasing interest from the beginning of the 1970s through until the 1990s by European healthcare systems to integrate patients and citizens 'at the core' of the system, the major problem evidenced by the literature is the high level of dispersion and fragmentation. Because of this, at the present moment, it is not possible to talk about patient involvement without talking about the opportunity to implement this in practice
 - b) The type of involvement (direct versus indirect): although patient involvement is generally associated with a democratic approach, the dominant method of engagement is indirect, instead of direct
 - c) The level of fragmentation or decentralization of the health system: patient involvement is more successful in centralized health systems (France, Germany, the Netherlands, UK), or in those that are decentralized but in fact operate in a centralized way than in decentralized health systems (Belgium and Canada).
- **Communication** Language, in terms of health literacy and especially use of technical terms, is an important barrier to good communication which is key for patient involvement
- **Personal** Personal characteristics of patients like ethnicity, age, disease and other relevant aspects may lead to discrimination, and therefore lower opportunities for involvement
- **Resources** There are two key aspects:
 - a) throughout the history of involvement the added value of patient involvement has not been quantified in economical terms and, thus has not been adequately compensated and
 - b) meaningful patient involvement requires resources.

Theory and Practice

Challenges

- Recurrent challenges were summarized by the literature and reported by individual countries. There is a high level of consensus and agreement irrespective of countries, experts and stakeholders on the following ones:
 - **Legal** In general, although a high level of individual patients' rights is guaranteed in the EU Member States, there is a gap in the view of patient involvement as a right. This applies especially to involvement in contexts other than individual clinical decision making
 - **Political** The lack of, or poor political commitment to patient involvement at all levels of the healthcare system and especially at policy making decision level is one of the strongest barriers
 - **Administrative** Patient involvement can be seen as an inconvenient, time consuming and interruptive to the smooth operation of a hierarchical, bureaucratic organisation especially if there is little or no knowledge on practices of involvement
 - **Professional** Despite progress towards acceptance of a more important role of patients, attitudes of health professionals remain a strong barrier
- Despite the acknowledgement of patient involvement as a core principle of patient-centred healthcare, the problem that remains unsolved by health stakeholders is the effective translation from theory to practice; from a theoretical patient involvement definition to its empirical implementation
- There is a high and uniform recognition of patients as central to the achievement of better efficiency, effectiveness and quality of healthcare systems. However the level of impact of patient involvement varies due to a complex set of variables that are responsible for a major or minor openness to patients and patient organisations' engagement
- Little comparative analysis has been done with respect to the evaluation, effectiveness and impact of patient and public involvement on health systems
- The approach and mechanisms used to involve patients have a consequence on the quality and impact of involvement. The majority of healthcare systems and countries choose information and consultation as a preferable mechanism to public involvement rather than the most formal and influential forms, that is to say delegation and control
- Patient empowerment is still very weak, undeveloped and, for some aspects, 'artificial' and ineffective. Even if we can distinguish three main levels of patient involvement, only one of these is sustainable in the time; that is the higher level of patient involvement where patients are part of the decision-making process.

HOW THE LITERATURE REVIEW FED INTO THE VALUE+ PROJECT

The findings from the literature led Value+ to explore the following issues in the questionnaire survey, the focus groups, workshops and interviews:

- The ambiguity of definitions of patient involvement and the concept of 'meaningful', and the definition of a specific framework to refer to
- Approaches to patient involvement and good practices
- Challenges and barriers as perceived by the various stakeholders engaged in the patient involvement process
- Factors supporting patient involvement
- The gender dimension of patient involvement in health-related projects.

Value+ used this knowledge also to shape the content of its deliverables: the toolkit for patients and patient organisations, the handbook for project coordinators and the policy recommendations to the EU Institutions.

Glossary





GLOSSARY

This glossary contains an explanation of some words used in the toolkit. We have included several terms, to make things easier for readers who do not yet have the toolkit in their own language. It includes simple explanations of words used in the EC, and in particular by DG SANCO.

We recommend anyone putting in a project proposal to check the official definitions carefully.

Action – a decision taken at a meeting that something will be done is often recorded as an action, because after the meeting someone must take action to ensure that it happens

Action-based research – research in which the researcher takes an involved role as a participant in planning and implementing change. Action research involves conducting social experiments by making changes while at the same time observing the results

Agenda – a list of topics or items which will be discussed at a meeting

Aims – the broad purposes which lie behind the planning for particular activities

Apprenticeship – an agreement where an unskilled person (an apprentice) works without pay or with a low wage, in order to learn a profession or trade from a skilled person

Articles – a legal term for a document describing how an organisation is run. This document may also be known as a constitution

Board Members – the individuals who come together in the special committee, called a Board, responsible for running an organisation

Buddy system – a system where a new person is paired up with an experienced person to be introduced to a new activity, or group of people. From the American term for 'friend'

Budget forecast or projection – a look into the future at how money will be spent over a period of time

Buzzword – a word or phrase connected with a specialised topic used primarily to impress, with a vague or imprecise meaning

Capacity – the skills, time and financial resources available within an organisation for a particular task

Capacity building – improving the skills of people in an organisation, to extend the activities in which they can take part

Carer – a friend or relative who provides unpaid, informal care for a patient, that is, not a paid care worker. The term is sometimes used for paid care workers in the UK, but not in this toolkit

Certified copy – a copy of a document that has been guaranteed as a genuine copy, for example by a government office, or a registered lawyer

Chair, chairperson – a person responsible for running a meeting

Chief Executive Officer (CEO) – the most senior worker in an organisation, responsible directly to the Board

Clinical trial – a procedure through which a new pharmaceutical product or treatment is tried out in humans for the first time, after passing other safety tests

Co-funding – the funding required from other sources to make up the difference between one funder's contribution and the total cost of the activity

Commissioner – the EU official responsible for leading the work of an EC department responsible for a specific policy area

Consensus – finding a consensus means that everyone involved discusses issues until they reach a position everyone can support

Consortium – a group of organisations which join together for a specific purpose; in an EC context, this would be to put in a funding proposal and carry out a project

Constitution – see articles

Consultative patient involvement – a type of involvement where patients/patient organisations are consulted, but they are not involved in the design of the consultation or plan which questions should be asked. They are not involved in the overall planning

Coping strategy – a method developed by an individual to make the best of a difficult situation

Critical path – a plan of the small steps necessary to complete one target in a larger plan

Deliverables – a business term used in EC-funded projects, referring to the things which a project will deliver to the EC, or make available to others, as a result of the project. These could be concrete items, such as a report, or an activity, such as a conference

Directorate-General – an EC department responsible for a particular policy area

Dissemination – refers to the process of making the results and deliverables of a project available not only to a specified target group or groups, but also more largely to all relevant stakeholders and the wider public

Diversity – understanding that each individual is unique, recognising and accepting our individual differences related to race, ethnicity, gender, sexual orientation, socio-economic status, age, physical abilities, religious beliefs, political beliefs, and so on

Egan's Skilled Helper – a model showing the steps in an interview, whereby a trained helper supports client to plan how to move from where they are now to where they want to be

Ethnicity – the shared and distinctive racial, national, religious, linguistic, or cultural heritage of a large group of people

European Commission – this body is responsible for carrying out the European Parliament's decisions and policies. It represents the interest of the European community, and is independent of the Member States

Evidence base – the facts upon which project proposals, funding, and policy should be based

Evidence-based knowledge – knowledge that is based on an evaluation of all the relevant information

Experts by experience – people who are experts in something not because of their education and training, but because of their life experience

Exploratory research – research into an issue or problem which has not been researched much before, to gain understanding for more investigation later

Financial turnover – the amount of money that passes through an organisation during a year

Focus group – a small group with specific characteristics selected from a wider population and brought together for open discussion, so that researchers can learn what their opinions are

Funder – someone, or some organisation, that provides finance for particular activities

Funding call – an EC term, referring to the invitation to submit proposals relating to specific topics within a particular policy area

Funding Programme – an EC term, referring to money that will be made available over a period of years, for specific purposes that support a particular EC policy area

Funding proposal – a plan prepared for funder, showing what an applicant for funding wants to achieve using the funding, and how it will achieve it

Gantt chart – a chart first designed by Henry Gantt, to plan the timing of tasks within a project

Gender – refers to the roles, behaviours, activities, and attributes that a given society considers appropriate for men and women

Gender Dimension – we have used this term to refer to planning a perspective relating to gender into patient involvement activities. This is sometimes referred to as gender inclusion

Governance – the internal systems and structures which enable an organisation to carry out its work

Grassroots – the ordinary people in a community or the ordinary members of an organisation. The leaders or those who are at the centre of political activity get strength and direction from the grassroots

Image – the way a person or organisation is seen by the public

Impact – when referring to EC-funded health-related projects, the ongoing effect that the project has on health policy, health service delivery, or healthcare after the project has finished

Internship – see apprenticeship

Involvement opportunity – a task for which experience as a patient or carer is essential but which requires a low or short time commitment. The task is therefore offered with a one-off payment, or with a request for volunteers, rather than being part of a paid position



Karpman Drama Triangle – a model which describes a triangle of relationships involving victim/persecutor/rescuer roles. A drama takes place in which the participants switch roles; the rescuer becoming a persecutor, the persecutor becomes a victim, whom the original victim tries to rescue. People who work as advocates with vulnerable people should be aware that this dynamic can occur and avoid falling into any of the roles, as it will make the advocacy issues harder to resolve

Kolb's Learning Cycle – a model showing four stages in learning. Individuals have preferred learning styles, and may start at any stage, but need to experience all four stages for learning to be complete

Lead partner – an EC term, referring to the partner which leads a project consortium

Links – working arrangements agreed between two or more organisations

Literature review – a review of what has been written on a particular topic

Marginalisation, marginalised groups – marginalisation means that a group of people is treated as if they were not important. A marginalised group is people who are treated in that way

Mental capacity – is the ability to make a decision. This ability may be lost due to many health conditions; sometimes this effect is only temporary.

In the UK a person has capacity for a particular decision if they:

- Understand information given to them
- Retain that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate their decision – this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.

A person may have the capacity for everyday decisions, for example what to wear, but no longer have the mental capacity for managing legal and financial matters.

Minutes – the written record of a meeting

Mission statement – an organisation's description of what it wants to achieve

Networking – getting to know people in other organisations, to exchange information

Non-governmental organisation (NGO) – an organisation that is not part of the state, or local government

Not-for-profit – an organisation whose articles does not allow it to run its activities for profit

Overspend – spending more money than has been allowed for in a budget

Participatory patient involvement – the involvement of patients/patient organisations in the design and carrying out of an activity or project, so that they have an ongoing influence

Participatory research – research which includes in the research plan, and in the research itself the people affected by the issue being studied

Partner – refers to an organisation which joins with others in a project, with a formal legal agreement

Patient – someone who receives healthcare

Patient involvement – means that patients take an active role in activities or decisions that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients

Patient-led patient involvement – Patients/patient organisations plan and lead the activities in which they are involved

Patient organisation – a not-for-profit non-governmental organisation (NGO) with members who are patients with a particular condition or their informal, unpaid carers, that is, friends and family

Patient representative – used in this toolkit for anyone from a patient organisation who represented patients

Performance indicator – something which is identified as a measure of how well a task, a project or an activity is being carried out

Policy officer – an EC project officer who focuses on policy

Politically correct – a term applied to language, ideas, policies, and so on which aim to avoid being offensive to groups of people identified by gender, race, culture, disability, age, socio-economic circumstances and so on

Project consortium – a group of organisations which join together for a project

Project co-ordinator – a worker appointed by the lead partner to run the project

Project officer – an EC official appointed to liaise with a project in all matters that concern the EC

Project partner – see Partner

Proposal – a plan prepared for a funder, showing what an applicant for funding wants to achieve using the funding, and how they will achieve it, see Funding Proposal

Qualitative methods – research methods which focus on understanding people's beliefs, experiences, attitudes, behaviour and interactions. They do not use numerical data. Qualitative methods include in-depth interviews, focus groups, documentary analysis and so on

Qualitative indicator – an indicator which focuses on how people experience an activity

Rapport – a relationship of mutual understanding or trust between two people, considered important for working with people, for example with information work

Regulatory barriers – any barriers related to public policies including policies embodied in statutes, ordinances, regulations, or administrative procedures or processes

Respondent – someone who replies to something, for example a questionnaire

Risk log – a plan of the possible risks which could affect a project and the measures which can be taken to reduce the risks

Scientific officer – an EC project officer who focuses on science

Secondment – a method whereby a worker is allowed to work with another organisation for an agreed period, before returning to his/her job in their own organisation

Socio-economic status – a person's background described in terms of their level of education, their employment (or lack of it) and the amount of money they have

Solvent – having enough money to meet financial obligations

Stakeholder – someone, or some organisation, who/which has an interest in a particular issue or decision

Steering group – a group of people who together make the major decisions about a project

Stigma – is the shame and disgrace attached to something which is regarded as socially unacceptable, and it leads to discrimination. Stigma is an issue for patients with many different conditions, and their families

Strategy – a long-term action plan for achieving the goals (specific targets) which support the objectives (broad purposes) of an organisation, or project

SWOT analysis – an examination of the Strengths, Weaknesses, Opportunities and Threats connected with a particular idea, or an organisation

Tender – a method of identifying the best organisation to provide a product or service. The people wanting the product or service (perhaps a local government department or large institution), make known what they want, and anyone interested in providing it makes a detailed application with their charges

Ticking the box – this refers to doing just enough to say something has been done, without paying attention to doing it well

Tokenism – making a symbolic gesture towards including people from a minority group, without allowing them to have any real influence, thereby giving a false impression of their involvement

Trustees – the individuals who come together in the special committee, called a Board, responsible for running an organisation

Umbrella organisation – an organisation whose members are organisations rather than individuals

Values – important beliefs or ideals shared by the members of a particular culture about what is good and desirable and what is not

Win-Win situation – a situation in which everyone in a negotiation or activity gains something that they want

Work package – a business term used in EC-funded projects for a set of activities which together are planned to meet one of the project goals, for example, a dissemination work package describes how the project results will be publicised

Workshop – meetings where participants are involved in group discussions and are normally organized around one or more theme areas. Workshops allow participants with differing values and priorities to build a common understanding of the problems and opportunities confronting them. The intent of most workshops is to either identify problems and expectations, or to recommend solutions.



About the European Patients' Forum (EPF)

The European Patients' Forum was set up in 2003 to become the collective patients' voice at the European level, manifesting the solidarity, power and unity of the European Union patients' movement. EPF is a not-for-profit, independent organisation and umbrella representative body for patient organisations throughout Europe. We currently represent 40 member organisations that consist of chronic disease specific patient organisations working at the European level, and national coalitions of patient organisations. In total, we reflect the voice of an estimated 150 million patients affected by various diseases in the EU.

EPF's vision is to establish patient-centred equitable healthcare through the European Union. Our core values emphasise a patient-centred approach to healthcare, inclusiveness, non-discrimination, patient empowerment, consultation and independency and transparency. We adopt a holistic interpretation of healthcare to include prevention, and the social, economic, environmental, cultural and psychological aspects of health.

EPF acts as a catalyst and consultative partner for positive change in EU healthcare systems and as a "watchdog", closely monitoring EU policy and legislative initiatives. We offer our members EU healthcare intelligence, and baseline patient rights policy responses to enable them to focus on disease specific responses. We support dialogue and negotiation among a broad range of EU level health stakeholders and facilitate the exchange of good practice and challenges of bad practice on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organisations at the European and Member State levels.

For more information visit www.eu-patient.eu

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Value+ “Promoting Patients’ Involvement in EU supported health-related Projects”

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