



The Value+ Handbook

For Project Co-ordinators, Leaders And Promoters
On Meaningful Patient Involvement



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Value+
Promoting Patients' Involvement
in EU supported health-related Projects

Project Leader: the European Patient's Forum

Project associate partners: Confederation Health Protection (KZZ), Bulgaria; empirica, Germany; European Institute of Women's Health (EIWH); European Men's Health Forum (EMHF); European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP); Health Policy Center of Lithuania (SPC), Lithuania; Spanish Patients' Forum (FEP), Spain.

Project collaborating partners: Agrenska Foundation, Sweden; European Federation of Allergy and Airway Diseases Patients Associations (EFA); European Multiple Sclerosis Platform (EMSP); Mental Health Europe (MHE); Retina International/Retina Europe.

Details about the Value+ project are to be found at: www.eu-patient.eu/projects/valueplus/index.php

The **Value+ Handbook** was compiled on the basis of the findings of the Value+ project.

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Dear Reader,

It is my pleasure to introduce you to the Value+ Handbook, one of a series of core resources that were produced as a result of the Value+ project.

Value+ grew out of a vision of the European Patients' Forum and our project partners on the need to exchange information on good practice relating to meaningful involvement of patients and patient organisations in European health projects supported by the European Commission.

The outcomes of such projects should shape health policy and decision-making, influence the direction in which research is heading and feed into the development of health technologies, treatments and services. These projects touch on so many aspects of patients' lives and experiences, that it is crucial for patients and patient organisations to be part of them.

The Value+ project has demonstrated unequivocally that meaningful involvement of patients enhances the results of health projects, thus enabling patients to contribute more effectively to policy towards patient-centred, equitable healthcare throughout the European Union. In conjunction with the resources made available through Value+, we have developed policy recommendations to reaffirm political commitment to meaningful patient involvement also at policy level.

The handbook was written to support project co-ordinators and project leaders and promoters of European projects in maximising the benefits of involving patients and patient organisations in European health-related projects.

We are confident that this handbook will help you to identify and approach patients and patient organisations, work effectively with them on a project, and address the opportunities and challenges relating to patient involvement in projects. It is worth reading alongside the Value+ Toolkit for patients and patient organisations.

Like the other resources produced by Value+, this handbook is the result of the contribution of many project co-ordinators, patient representatives and patients who enriched it with their insights and knowledge. We are grateful to you all for your engagement, for sharing your views and experiences and making this handbook possible.

We would very much welcome your suggestions and feedback on how to improve the Value+ Handbook. We would also like to enhance the document with more illustrations of projects, and project experiences. We would be very pleased to hear about your project's patient involvement activities. Kindly send Value+ any details to info@eu-patient.eu.

Warmest regards,

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

Anders Olauson
EPF President



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Introduction



The Value+ Handbook aims to enhance the opportunities, quality, and results of involving patients in European health-related projects.

The Value+ project **Promoting Patients' Involvement in EU Supported Health-Related Projects**, led by the European Patients' Forum (EPF), decided to investigate the challenge of how patients and patient organisations can be meaningfully involved in European Commission (EC) co-funded projects on health issues.

Value+ wanted to know what has been happening in relation to patient involvement over the past ten years in European health-related projects. It was also keen to shape understanding on what could happen in future projects by, with, and for patients.

This handbook is one of several core documents that Value+ has produced. They include a literature review on patient involvement, policy recommendations targeted to the European Union Institutions and Member States, and a toolkit for patients and patient organisations. There is a great deal of synergy and complementarity among all these documents; they can be read together as part of a package, or individually for specific needs.

The handbook is written for project co-ordinators, project leaders and project promoters of EC co-funded projects who may or may not themselves be members of patient organisations. We assume, that many readers will not be either members of patient organisations or patients; therefore they may not be familiar with aspects of patient involvement that the handbook addresses.

Within the Value+ project, we have used the term 'patient representative' to refer to anyone from a patient organisation which 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 family members of patients, without being part of a patient organisation.

The intention of this document, as with all Value+ work, is to enhance the opportunities, quality, and results of involving patients and patient organisations in European health-related projects. This aim presents substantial positive challenges for project co-ordinators, project leaders and project promoters whether or not they have already experience of working with patients or their representatives.

In this sense, the handbook offers advice, evidence, examples, and signposting to further information that can be useful to its readers whatever extent of experience in patient involvement they have.

A tip for reading the handbook: all the words which are underlined are described in detail in the glossary of terms at the end of the handbook. It is easy and worthwhile to turn to the glossary for a brief definition of any complex term. We hope we have captured all the terms that the readers might need to know about.

1.1 AIM AND CONCEPT OF THE VALUE+ PROJECT

Value+ aimed to promote patient involvement in EC co-funded projects by exchanging information, experiences and good practices among key stakeholders in relation to meaningful involvement of patients and patient organisations.

Value+ created a snapshot of patient involvement in terms of European projects.

Value+ viewed meaningful patient involvement as a means to enhance the results of projects, and to contribute to the development of patient-centred, equitable healthcare policy throughout the European Union (EU).

On this basis, the project wanted to achieve:

- A comprehensive evidence-based overview of current practice and trends regarding patient involvement in EU health projects
- An extensive analysis and reflection regarding critical success factors, challenges and hurdles regarding patient involvement
- The identification of good practices in patient involvement to inspire and motivate key players at policy, programme and project levels
- The development of very specific targeted resources.

1.2 WHAT DID THE VALUE+ PROJECT DO?

The Value+ team decided to use qualitative study methods to explore the field of patient involvement because this topic had not been investigated before in European health-related projects. The focus was on projects that are connected with chronic diseases or recurrent conditions.

We took a field research or case study approach. Even when undertaking the questionnaire survey, we favoured a qualitative approach that used largely open-ended questions.

This kind of exploratory approach is suited to relatively early stages of study in particular fields. It is also appropriate in terms of exploring a more process-related subject or one which simply involves people. Value+ covered a lot of new ground. No previous project or organisation had explored precisely what was happening by way of patient involvement in European co-funded health projects. There were also no specific EU guidelines to support patient involvement in this type of projects at the time of writing.

In terms of methodology, we initially investigated what had been happening in terms of patient involvement in the available literature that had received a peer review. We also drew on other published literature from international organisations such as the EC and the World Health Organization (WHO), and books, pamphlets and literature published by various patient organisations, health authorities, and non-governmental organisations.

Based on the findings of this literature review, we undertook a questionnaire survey of all the projects that we could identify over a ten-year period that could have involved patients. The projects were distributed throughout many different subject areas supported by the EC; they included public health, employment, information and communication technologies, education and research. From this large sample, we selected a number of projects illustrating how diverse good practice in patient involvement can be.

Value+ also worked with a number of current projects with the aim to find out what might support projects to involve patients well, and to encourage them to include more patient involvement in their work.

A key aim and feature of Value+ was to identify the difference between patient involvement and what it considered to be meaningful patient involvement. As a result, we intended to develop a framework or model of patient involvement that could be used as a reference in projects.

For this purpose, we tested out the meaning and importance of patient involvement in discussion with patients, patient representatives, and project co-ordinators from non-patient organisations in focus groups and workshops. The workshops also promoted patient involvement by organising capacity-building seminars focused around building advocacy skills of patients and patient representatives. Value+ ended with a large, international conference that attracted some 100 persons and was web streamed to enable many more stakeholders to be involved both in 'real time' and after the event.

Value+ aimed to be an example of good practice in its own right in terms of patient involvement. With this in mind, it made sure that the majority of project partners were patient organisations and patients. Moreover, it arranged for its own work to be evaluated¹ continuously by an independent evaluator. This evaluator followed the project throughout its duration, attended some of the project's meetings, and sent evaluation questionnaires to the project team members (and others). The focus of this evaluation was on the project's process and outcomes.

¹ The Value+ project used the notion of 'evaluate' in a situation where the EC often uses the term 'review' instead. In Value+ terms, evaluation needs to be understood as an ongoing, continuous process of commentary and enhancement of processes that took place throughout the duration of the project.



1.3 ACHIEVEMENTS OF THE VALUE+ PROJECT

As a result of the work described, Value+ created a snapshot of what patient involvement is in terms of European projects and made a set of proposals with regard to what patient involvement could become. It expanded these proposals to relate to other, wider, forms of patient involvement e.g., in decision-making related to healthcare systems and services, and to patient involvement in policy development.

The project outcomes have taken many forms. In addition to this handbook, we produced:

- A toolkit for patients and patient organisations to support them in getting meaningfully involved in projects
- A set of policy recommendations calling on the EU Institutions and Member States to reinforce their commitment to patient involvement
- A database of European health-related projects with patient involvement
- Examples of good practice
- A literature review
- A directory of European and national patient organisations
- An overview of patients' rights in the Member States.

All of these deliverables are accessible on the Value+ website.

How to find out more about Value+

Details about the Value+ project can be found in two places. Look on the project website or submit a request to the project co-ordinator, the European Patients' Forum. See:

www.eu-patient.eu/projects/valueplus/index.php/

www.eu-patient.eu/about_us/contact_us.htm

All About the Value+ Handbook

The handbook is focused on how to involve patient organisations and patients in European Commission co-funded health projects.

This chapter examines who the potential readers are, what this handbook is, what it contains, and what the links with the Value+ [Toolkit](#) are.

2.1 TARGET READERS

The Value+ [Handbook](#) is a guide for **project co-ordinators**, **project leaders** and **project promoters** of EC co-funded projects that are health-related.

In Value+ terms, a project co-ordinator is a staff member in charge of managing a project within an organisation; a project leader is the organisation which leads the consortium implementing a project; a project promoter is an organisation or an individual promoting politically or financially a project without necessarily being involved in its implementation. Throughout the handbook we refer to all of them collectively as [project actors](#) and we name them individually when what we write is specific to one of them.

We envisage that other potential readers could be:

- People who plan to be co-ordinators of European health-related projects
- Patient organisations which, or patients who, want to play a part in a European co-funded projects
- EC personnel such as project officers.

The handbook assumes that most readers will not be from patient organisations, may not have any experience of being a patient and may have little or no previous experience in involving patients and patient organisations in projects.

Project actors will have different levels of experience relating to the project's topic of concern (whatever the subject matter is e.g., health, research, policy, or technology), to project coordination and to patient involvement.

Whatever their individual role is, all project actors are likely to need information on:

- What they as co-ordinators, leaders and promoters need to know about patient involvement
- How they can concretely involve patients and their representatives.

Finally, EC personnel may wish to read this handbook and to recommend it to the projects with which they liaise. These officials include [project officers](#), [policy officers](#), or [scientific officers](#) who may head up different sectors of expertise or even particular departments or units.

2.2 OVERVIEW OF THE HANDBOOK

A handbook is a [reference book](#) which offers concise, factual information on a specific subject. It is intended to provide reference materials for its readers, organised systematically for quick and easy access.

The handbook assumes that most project co-ordinators and project leaders already know about running a project at least in theory, if not in practice. For this reason, we have not specified how to manage European projects. We have, however, make some generic observations about European projects and their characteristics.

The handbook contains six chapters and some annexes.

The information in each chapter is as precise and factual as possible. Some chapters contain a number of tips or '[how tos](#)'. This is particularly so in Chapter 5 about projects, and Chapter 6 about working with patient organisations.

The chapters explain the main aspects of patient involvement in health-related projects. The topics are:

- What the Value+ project was about
- Purpose and readership of the handbook
- Why involving patients in projects is important
- What patient involvement and meaningful patient involvement are about
- Identifying and approaching patients, patient organisations, and other support groups
- Working with patients and patient organisations in a project
- Capacity-building issues related to patient involvement in projects.

One of the handbook annexes provides a list of useful [reading material](#) that includes many of the most relevant articles, books, papers, and websites on different aspects of patient involvement in projects.

For this reason, the handbook does not include a traditional bibliography. Nor does it cite [references](#) throughout the book in the way that a more academic document would do.

There are quotations and illustrations of facts and figures about health-related projects. These are boxes located throughout the handbook that contain simple quotes or pull quotes. They are to be found particularly at the start of each chapter. Simple quotes are taken from the handbook text directly. The pull quotes have been taken from comments made by members of projects that the Value+ team has studied. For example, they are project members to whom the Value+ project has sent questionnaires, and with whom it has undertaken interviews or held focus groups. The various focus groups organised by the Value+ project have enriched the general thinking of the Value+ team, and they have given patients and other stakeholders involved in the project a distinct voice.

2.2.1 The handbook annexes

The handbook has several annexes.

The first of these annexes (Annex 1) is a glossary. Wherever a word in the handbook is underlined, it is described in more detail in this glossary. Readers need to turn to the glossary for more explanation on any underlined words.

A second annex (Annex 2) concentrates on good practice in patient involvement in European projects.

A third annex (Annex 3) focuses on pointers for how and where to find information on patient organisations, patients' conditions and patients' rights.

The last annex (Annex 4) contains some tools developed by Value+.

2.3 RELATIONSHIP BETWEEN THE VALUE+ HANDBOOK AND THE VALUE+ TOOLKIT

A toolkit is a collection of tools. The Value+ team has developed a number of tools that are collected in a companion volume to this handbook called the Value+ Toolkit.

The Value+ Toolkit contains models, methods, and techniques that patient organisations and patients may use to facilitate their involvement in a European project. It is aimed at patient organisations which and patients who want to play a part in a European project. It may also be of use to anyone else who wishes to involve patients in a project and for this reason project actors could benefit from reading it.

The two documents are complementary. The handbook sometimes draws on work developed in the toolkit, including some tools that the Value+ team has created or improved and that are described in far more detail in the Value+ Toolkit.


Where relevant throughout the handbook, reference is made to the Value+ Toolkit. Where there are complementary links between the handbook and the toolkit, the handbook highlights these.

The toolkit has useful sections that describe ways and means of overcoming various barriers to meaningful patient involvement in health-related projects. Various parts of the toolkit are strong on ways of communicating with patient organisations, on overcoming various causes of stigma for the patients or patient representatives who wish to get involved in projects, and developing good practice in involving patients as volunteers or fellow workers.

Chapter 4 of the toolkit is helpful in describing matters that patient organisations need to be aware of and that can help them in preparing for getting involved in an EC co-funded project. These include: understanding the administration involved in preparing a proposal and running a project according to EC requirements; how to become a partner in projects; how to overcome a lack of information and knowledge about funding programmes; and how to build partnerships with patient organisations.

Why is Patient Involvement in Health-Related Projects Important?





Citizens in Europe are increasingly called on to act as the masters and mistresses of their own health and well-being.

The Value+ project has concentrated on the meaningful involvement of patients and patient organisations in European projects.

As background, it is useful to understand the general trends that are taking place in Europe on patient involvement, since these shifts lie behind the developments in many European projects.

Patient involvement is increasingly important in the health systems of Europe today. It will become even more important in the future because it is at the heart of improvements needed by European health systems and services.

Overall, it is particularly useful to distinguish between involving patient organisations in projects, and involving individual patients. The two approaches are possible but substantially different. Involving a patient organisation may give greater legitimacy and accountability to the involvement because the patients who are nominated will be representative of the interests of patients with a particular disease or condition, and will act in representing them as a community.

This chapter looks at the general background to patient involvement as expressed in the literature. It also outlines some of the more political reasons for encouraging patient involvement, and finally highlights how projects can benefit from involving patients and patient organisations.

We consider that, having such a broad vision of patient involvement is particularly important for the project actors of EC health-related projects.

3.1 WHAT THE LITERATURE SAYS ABOUT PATIENT INVOLVEMENT

The Value+ team undertook a literature review on patient involvement through a rigorous search of the Medline Plus database. We had access to academic and scientific articles and articles published on the Internet. A systematic review of the barriers, models, and trends to patient involvement was covered.

Literature from various international organisations such as the EC, the Organisation for Economic Co-operation and Development (OECD), and the World Health Organization (WHO) were explored by the project. Literature from seven specific countries was also accessed: two countries were from outside the European Union – Australia and Canada, and five were from within the Union – Denmark, Finland, France, Germany, and the United Kingdom.

An executive summary of the literature review and the full report outlining all the literature uncovered are available at:

www.eu-patient.eu/projects/valueplus/resources/attached_documents/valueplus-literature-review-on-patient-involvement.pdf

The literature review showed the Value+ team a great deal about what academics and researchers have to say about patient involvement in healthcare. Even though it offered very little information about what patient involvement means in terms of European health-related projects specifically, there are some insights enforcing the importance of involving patients and their representatives that are valuable also in a project context:

- 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.
- 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 the degree of openness to patients and patient organisations' engagement.

Why is Patient Involvement in Health-Related Projects Important?

- Patient empowerment is still very weak, undeveloped and, for some aspects, 'artificial' and ineffective. Although we can distinguish three main levels of patient involvement, only one of these is sustainable over time; that is the higher level of patient involvement where patients are part of the decision-making process.

3.2 BENEFITS OF INVOLVING PATIENTS AND PATIENT ORGANISATIONS IN A PROJECT

Project co-ordinators and project partners who are not themselves patient organisations often have little knowledge of patient involvement. Patient organisations therefore have a core role to play in educating and supporting health professionals, civil servants, policy makers, and researchers involved in projects about patient involvement.

Value+ identified a number of benefits that patients and patient organisations can bring to projects. Those we highlight below were voiced by the project co-ordinators of European projects in a workshop organised during the course of the project:

Motivation Patients and patient representatives show a very strong commitment towards achieving results and have remarkable motivation in being involved and contributing. Value+ experienced clear examples of this motivation. A patient (representative of a patient organisation at the same time) involved in the Value+ Steering Group dedicated his free time to the project. Some patients who participated to the focus groups cancelled personal previous engagements or travelled with difficult health conditions to be present and offer their views.

Addressing appropriate issues Patients understand the patterns and experience of their disease best. The perspective they bring is extremely helpful in ensuring that a project makes a correct and comprehensive problem analysis and sets objectives and activities that will contribute to finding solutions to the issues identified, and ultimately bring benefits to the patient community.

Validating project outcomes The input of patients and their representatives is important not only for defining needs but also for validating the results of a project, whether those are good practices, guidelines, policy recommendations, services or technologies. If these are not welcomed by patients as useful, they will not have much impact in the long term.

Dissemination The EC places great emphasis on the dissemination of the outcomes of projects to health stakeholders so that there is an efficient sharing of good practices and knowledge. Clearly patients and patient organisations are key addressees of this information as well as important channels to deliver it. Patient organisations' contacts with grassroots patients are crucial for effective project dissemination work.

Patient-friendly communication Health projects often produce communications targeted explicitly at patients or that have to be accessible also to patients among various other audiences, e.g. brochures, guides, websites. Patients and patient organisations are best placed to advise on how to define messages, in what form these should be delivered, through which channels they should be communicated, and finally on accessibility issues for patients with impairments.

Funds Project co-ordinators were of the opinion that patients and patient organisations can bring financing. There are patient organisations with high status, visibility and capacity which can attract funds. Moreover, the EC as well as other funders are increasingly keen to ensure involvement of key stakeholders in projects, including end-users. Having a strong patient involvement can therefore be considered an asset, and may influence positively the EC project evaluation teams in charge of selecting projects to recommend for funding.

Empowering patients Project co-ordinators thought that it is necessary to strengthen the influence of patient organisations to give patients a more important place in the decision-making. In a project context, such empowerment translates into the stronger capacity of patient organisations and patients to contribute to the project work.

There are a number of benefits described by patients and patient organisations that are detailed in Section 2.3 of the Value+ Toolkit.

3.3 THE POLITICAL “WHY?” OF PATIENT INVOLVEMENT

Patient representation in healthcare decision making and planning is an essential element of such empowerment. In addition, patient involvement should become a baseline performance indicator of health systems.

Commissioner Vassiliou, formerly of DG SANCO,
[www.eu-patient.eu/publications/
EPF_HealthLiteracyConference_2008_Report.pdf](http://www.eu-patient.eu/publications/EPF_HealthLiteracyConference_2008_Report.pdf)

The White Paper **Together for Health: A Strategic Approach for the EU 2008-2013** (October 2007) states that *“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”*².

The Council of Europe Recommendation No. R (2000) 5 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.

A number of European Member States have begun to establish patients’ rights in either their laws or in patient charters. An overview of such legislation is available at www.eu-patient.eu/projects/valueplus/resources/attached_documents/overview-of-patients-rights-in-the-member-states.pdf

These political and legislative developments clearly show that moving towards more patient-centred healthcare systems is a declared goal of all European healthcare policy makers.

There are basically three reasons for these developments:

- European citizens have voiced their demands for more information about the quality and safety of their own care and the care of others. These voices are increasing in number as an awareness of the multi-dimensional character of health increases
- A desire to increase the legitimacy of EU policy outputs by strengthening the involvement of stakeholders, including patients
- At the socio-economic level, the costs of healthcare are increasing.

Four issues can be summarised as the main elements of such socio-economic pressures:

- Demographics are changing in Europe, and there is especially a growth in Europe’s population of older adults and a reduction in the numbers of young people
- The increase in the number of people with chronic diseases, and the challenge that this is placing on Europe’s health systems and services
- Resource pressures on what is often called the benefits basket
- Increases in the co-payment of healthcare that is expected from individuals and from organisations.

Citizens in Europe are increasingly called on to act as the masters and mistresses of their own health and well-being. This increased responsibility on the part of patients also needs to be balanced by increased rights that are being recognised, and provided, by the various Member States. Many Member States are trying in return to offer patients and citizens new responsibilities, i.e., for staying healthy and co-managing their condition.

Such shifts in the concept of responsibility will have to lead to a greater level of involvement of patients. It is important to introduce this expansion in responsibility-taking and involvement in parallel with a means of capacity-building. New tasks and responsibilities that patients may need to take on both individually and collectively are worthwhile trialling and piloting.

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

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

Why is Patient Involvement in Health-Related Projects Important?

This shift will influence – it already does – how patients are involved in health projects. All partners in European health-related projects are likely to have to learn a greater understanding of each others' needs, preferences, and preferred ways of working. Equally, they may have to learn to make compromises and come to a consensus about how bridges can be built across what may have previously been impenetrable borders.

Clearly, there is a huge amount of activity that still needs to be achieved to make progress on meaningful patient involvement in European projects. The same can be said of projects that are taking place at the level of different countries, regions, and municipalities. Some countries are making rapid strides forward. Others probably need every bit of support that their patients, together with their health professionals, policy makers and health authorities can get.

The Value+ team hopes that its first steps along this journey can be followed by even larger, positive, steps in the years to come.

In this light, Value+ has itself made a number of policy recommendations that relate to how greater patient involvement in health decision-making can move forward. These proposals are not limited to the context of EC co-funded projects with a health orientation; they have been expanded to encompass means of getting patients involved in health policy more widely. The proposals relate to patients' right to involvement, resourcing, and capacity-building. They cover a large portfolio of constructive and concrete suggestions.

On resourcing – particularly in relation to EC health-related projects – the recommendations focus on eligibility criteria, contact points, waiving of co-financing procedures, simplification of application procedures, and access to funds at national levels. On the right to involvement and capacity-building, they include: targeted policy documents, guidelines, codes of practice, and monitoring and evaluation systems.

It is very much hoped that these proposals and suggestions could in future have important constructive meaning for project co-ordinators keen to involve patients more actively in their EC health-related projects.

Value+ Policy Recommendations are available at:
www.eu-patient.eu/projects/valueplus/resources/attached_documents/policy-recommendations.pdf

What is Meaningful Patient Involvement?



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.

This chapter offers insights into both the patient involvement aspects of a project's content and its management.

On the one hand, organising a project that includes meaningful patient involvement is likely to be challenging for non-patient organisations. On the other hand, a patient organisation that runs a health-related project which seeks to encourage patient involvement may find its major challenge is to work with the partners in a team which are not other patient organisations.

Encouraging and advocating patient involvement implies a high level of commitment on behalf of the project co-ordinator, the project partners, and the patients or patient representatives.

Other issues that relate to equity and equality may be particularly important for patients. In terms of equity, this chapter focuses on the example of gender in so far as it relates to the meaningful involvement of patients in projects. Other aspects of equity (beliefs, disability, faith, philosophy, ethnicity or religion) would require similar depth of treatment. We selected gender as an illustration.

Overall, this chapter examines what the Value+ team itself meant by patient involvement, and particularly meaningful patient involvement.

4.1 WHAT PATIENT INVOLVEMENT AND MEANINGFUL PATIENT INVOLVEMENT MEANT TO VALUE+

The review of the literature on patient involvement has highlighted that while there is diversity across European and non-European countries about the manner in which to interpret and implement patient involvement into the healthcare system, there is still a common challenge concerning the concept of *meaningful* patient involvement.

The notion of meaningful in relation to patient involvement has been coined by Value+. Other notions commonly used could be 'quality', 'extent', 'level', 'impact' of patient involvement. All of them aim to qualify involvement. However, are these terms clear? What does quality or level of patient involvement really mean? A patient and a project co-ordinator might give very different replies to this question.

Even without a specific notion attached to it, the concept of patient involvement on its own may be understood and interpreted differently. The Value+ team asked patients, patient representatives and project co-ordinators to give their own definition of patient involvement; these definitions were very diverse.

It is due to this ambiguity and lack of a common vision of patient involvement that the Value+ team decided to study meaningful patient involvement.

Patients and patient organisations are strongly motivated to help develop health policy, treatments and healthcare that really do meet patients' needs. Although patients are willing to give their time and effort to health-related projects, there are often barriers and challenges to overcome.

Involvement in projects may not always have been a satisfactory experience for patients. It is important that we learn from these previous, negative experiences.

4.1.1 Definitions of meaningful patient involvement

Value+ did not have a ready-made definition to offer and use to assess the projects. We wanted patients to share what would make patient involvement meaningful for them. We asked the respondents to the survey questionnaire to give their definition and we discussed this with patients at Value+ focus groups and seminars.

The focus initially was on finding a definition that would relate to projects. Eventually, the Value+ team decided that a more general definition was needed and could be useful in different contexts. This definition can apply to involvement of individual patients or patient organisations in participatory or patient-led activities.

As a result of this process Value+ proposes the following definition, which has been endorsed through Value+ various forms of consultation.

What is Meaningful Patient Involvement?

Value+ Definition of Meaningful Patient Involvement

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.

4.2 VALUE+ MODEL OF MEANINGFUL PATIENT INVOLVEMENT IN PROJECTS

Value+ did not content itself with establishing a definition for meaningful patient involvement; we also wanted to create a framework that could be used in future projects to plan, develop, implement and assess the involvement of patients in European projects.

This framework consists of:

- A Definition
- A Model of Meaningful Patient Involvement
- Indicators for Meaningful Patient Involvement
- Assessment Grid of the Value+ Model of Meaningful Patient Involvement
- Value+ Levels of Patient Involvement.

Whereas the Model represents a conceptual framework for involving patient organisations in projects, the other items listed are instruments that project actors may use concretely in projects, no matter what the project topic is, whether patients or patient organisations are involved, and whether the project is European or a national one.

Although this framework is developed with the aim to be applied for whatever type of project, there are aspects that project actors might need to adapt to fit their purposes and needs. This framework has received input and comments from a number of people the Value+ team consulted; it has been therefore been developed with and endorsed by patients and patient representatives. The framework is drawn entirely from the Value+ Toolkit, for which it was initially developed.

We describe the Value+ Model below; the other items are in Annex 4.

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 organisation and grassroots patients after their involvement in the project has ended about the impact of the project results once the project ends.

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.

Value+ has also created several tools which can help project actors deal with certain aspects of patient involvement. These tools can be useful both with the patients and patient organisations that are engaged in the project but also with the other project partners.

- 'Involvement opportunity checklist': A Value+ tool for describing an involvement opportunity
- 'Short involvement opportunity information sheet': This is an example that Value+ used to invite participants to a focus group
- 'Value+ Gender and Patient Involvement in Health Projects Information Sheet': This document highlights key elements project actors should consider to ensure gender equity in involving patients in their projects. It was developed by Value+ partners with expertise in gender: the European Men's Health Forum (EMHF) and the European Institute of Women's Health (EIWH).

All these tools can be found in the Value+ Toolkit and Value+ website.

Another useful set of guidelines are those developed by the International Alliance of Patient Organisations (IAPRO), www.patientsorganizations.org/showarticle.pl?id=591&n=962. These guidelines were written for any organisation that desires to involve a patient organisation or patients.

4.3 EQUITY IN PATIENT INVOLVEMENT IN HEALTH-RELATED PROJECTS

The TREAT-NMD project is undertaking research to explore, identify and examine ethical and social issues in clinical research of neuromuscular disorders.

One of the tasks of the research group in charge of this work is to monitor gender equality in TREAT-NMD.

See www.treat-nmd.eu/home.php/

Many different aspects of patients' rights are important. In relation to the equality of patient involvement in European projects, it is important to be aware of several crucial issues. For individual patients, these include the patients' sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

The Value+ team decided to concentrate on issues that relate to patients' involvement in projects in terms of their gender. This choice was made because gender is one of the most concrete, evident, and emergent issues in terms of patient involvement. It also serves to illustrate the considerable work needed in relation to other areas of diversity. Furthermore, there is already an EC requirement to consider gender in projects, so there was an opportunity to look at the impact of that requirement. The contribution of EMHF and EIWH was crucial to unfold this aspect of patient involvement. They contributed significantly to this chapter.

4.3.1 Gender and patient involvement in health-related projects

Gender should definitely be considered in relation to health. Women and men should be treated equally wherever they have common needs. At the same time, their differences should be addressed in an equitable manner.

Sufficient attention has not yet been paid to gender in European health-related projects. This is especially the case with regard to patient involvement. Focus, study, and research on gender and health is developing fast. There are so far no clear EU guidelines to support gender considerations for patient involvement in health-related projects.

It is, however, hoped that the information in this handbook will help to support:

- More informed considerations of gender
- The way in which these considerations can enhance patient involvement.

4.3.2 What is gender and why it is important in health-related projects?

Women and men are different in relation to their biological make-up (i.e., their sex). Women's and men's biological susceptibility to disease and response to treatment can be different.

Gender refers to women's and men's different roles and responsibilities in society, their access to resources (including information), their control of resources, and their decision-making power. Gender-based roles can have a direct impact on health. These differences can have a dramatic effect on women's and men's:

- Health needs
- Health attitudes and behaviours
- Roles in relation to health and healthcare.



Women bear a disproportionate burden of care for their family members. Care work is generally associated with a traditional women's role and it is often largely undervalued. This burden of care that women carry can contribute to significant other health problems.

Men are often socialised to value risk-taking behaviours. They are less likely to seek help and support for their health problems. They are also more likely to lead unhealthy lifestyles and to seek access to health services late.

People are born female or male but learn to be girls and boys who grow into women and men. This learned behaviour makes up gender identity, determines gender roles and gender related health behaviours.

Women's and men's biological susceptibility to disease and response to treatment can be different. Symptoms, and responses to medicines, can vary according to whether a patient is a woman or a man.

Historically, women have often been under-represented as the subjects of scientific studies. This has at times resulted in female patients being treated with medicines that have not been adequately tested on women.

There are differing ways in which women and men need to be approached with regard to health information, promotion, prevention, and disease management. These 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. It can also create the under-representation of patients of one gender in projects where they should be represented in larger numbers.

Examples of particular health conditions, to which projects may be related, and where the genders may be under-represented include attention deficit and hyperactivity disorder, cardiovascular disease, depression, eating disorders, osteoporosis, and lung disease:

- Cardiovascular disease is a major killer for men under 65. It is often labelled as a male disease. Most studies have been carried out on men. Female symptoms can be different. They are often not diagnosed properly, even if heart disease is the number one killer of women overall

- Osteoporosis is often considered as a female-only disease. However one in five men develops the condition, many of whom are misdiagnosed
- Attention Deficit and Hyperactivity Disorder and lung disease (including lung cancer) may affect significant numbers of girls and women
- Depression and eating disorders may be experienced by boys and men.

There are, of course, other conditions that are perceived commonly as affecting only one sex and not the other. Nevertheless, a significant proportion of members of the other sex may experience these diseases.

4.3.3 Benefits of and tips for focusing on gender in health-related projects

Unless there is evidence to the contrary, both women and men should be equally included in any project.

Women and men have different gendered experiences of their health. It is therefore important that both their views are reflected in health-related projects.

Project outcomes may impact differently on end-users according to their gender. The project design, including the research methods, and its implementation must take account of gender differences among patients.

Selecting a mix of female and male patients and patient representatives that reflects the expected impact of any project outcomes on women and men respectively, is more likely to meet the needs of patients according to their gender. Having a gender-sensitive approach to recruiting and involving patients in projects is important. Patients' opportunities for participation in projects must take account of gender differences.

Male patients are less likely to volunteer unless they are approached specifically. Their contribution to health-related discussions is most effective in male-only groups when they are acting purely as patients. (It is, however, contended that this is possibly not the case when men are acting in a professional capacity).

Sex-disaggregated data (i.e., data that can be distinguished according to whether the patients are women or men) is needed to assess the impact of the project outcomes for both women and men.

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Main benefits of gender consideration in patient involvement Involving both female and male patients and patient representatives in health-related projects can:

- Ensure more equitable outcomes by ensuring gender specific needs are also met
- Ensure gender equality by avoiding discriminatory practices on the grounds of gender
- Increase the likelihood of a richer mix of perspectives and contributions that result directly from patients' gendered experiences
- Increase the authenticity and corrective function of patient feedback
- Ensure the adequacy of project outcomes in relation to the needs of the patients concerned.

Questions on gender for project co-ordinators

Here is a list of questions that can be used by project co-ordinators to help them orient their projects towards good practice in gender awareness. These questions can help to ensure that gender is considered in health-related projects in relation to patient involvement.

The questions are worded generally enough that they can be adapted to projects with other topics that also involve women and men.

Questions on gender for project co-ordinators

Has the project considered whether its findings and outcomes may have different impacts on patients and other end-users depending on their gender?

Is there equal participation of women and men among the patients involved in the project, or should the mix of female and male patients be aligned with expected project outcomes?

Have female and male patients or patient representatives been involved in all stages of the project's development and implementation?


Have any data collected and/or used by the project been sex-disaggregated?

Have materials been developed that will appeal to both genders or designed for each specific gender?

Are the appropriate project materials marketed to women and men respectively?

Does the project's dissemination strategy take into account the needs of both genders?

Co-ordinating Projects to Involve Patients Meaningfully



Health is an all-encompassing aspect of people's lives. As a result, there are many different types of projects that focus on it.

This chapter looks at project co-ordination from the perspective of patient involvement. Where feasible, it especially targets European health-related projects and outlines the different kinds of projects that a project co-ordinator can expect to coordinate.

The chapter describes the typical different stages of projects and focuses on the patient involvement aspects of project coordination and project management for those stages.

It assumes that a project co-ordinator of a health-related project, whether it is large or a small project, will probably need to involve a patient organisation.

It raises awareness of and gives guidance on:

- How a project actor could promote the particular project to a patient organisation or to patients
- How a project actor needs to support the patient organisation or patients
- How important it is to involve patients and their representatives in project bodies charged with overall coordination and decision-making
- The benefits of patient organisations leading specific activities
- How complex eligibility criteria currently are for patient organisations
- How patient organisations and patients might benefit from having specific contact points or persons.

This chapter is not a how-to guide on project coordination or project management. It does not prescribe how to manage European projects. Rather, it assumes that most project co-ordinators already know about running a project, at least in theory if not in practice. It does make some generic observations about what European projects are like, and what their characteristics often are as a form of background.⁴

5.1 BACKGROUND TO HEALTH-RELATED PROJECTS AND GETTING PATIENTS AND PATIENT ORGANISATIONS INVOLVED

Generally, project coordination incorporates both the content of a project (whether scientific, technical, or political) and its actual management. In some projects, these dual responsibilities are held by the same individual and organisation. In others, they can be separate. Much depends on the size and complexity of a project.

Basically, the larger and more complex a project, the more challenges there will be to run it – although, anecdotally, this is often disputed by project co-ordinators who say that comparatively much more energy and resources are devoted to managing a small project than a large project.

Projects may have different degrees or depths of specialism. A project may be an in-depth research project, it may facilitate a consultation exercise, or it may be a means of capacity-building in areas that require resources.

Patients and patient representatives who are attracted to be involved in a project may already be experts in a particular specialism in their own right. Individual patients may wish to be included in a project as a means of enhancing their skills and capacities in new fields or areas. All sorts of tasks and skills that patients of diverse backgrounds might seek to enhance can be imagined.

Of course, patients who are ready to take on involvement tasks are in fact experts in the management of their own disease or condition; this can be an important reason in its own right for their involvement in a particular project.

The patient organisation may be one partner among many. It is important for the organisation preparing a proposal to think carefully about what the project wants to achieve and how it will achieve it before it invites a patient organisation to join in the project consortium, just as it would with other prospective partners.

⁴ There is plenty of official material available from the EC on the subject of project co-ordination and management. There is also a great deal of literature on project management and organisation available more generally.

Vice versa, if a patient organisation is leading the search for a consortium, it needs to think carefully about how the other consortium members can contribute. Neither party should promise more than it can provide (whether in terms of resources, assistance, or support). Both parties need to think carefully, and plan for, the support that they need to give to each other as the proposal, and then a successful project, develops.

The process of planning patient involvement begins at the project proposal stage. It should be monitored throughout the project so as to understand when and where any adjustments are desirable. Improvements to patient involvement can therefore be made throughout the lifecycle of the project.

5.2 DIFFERENT TYPES OF PROJECT

The Euroguide project has gathered information about genetic testing, counselling and research across Europe, by involving patient organisations and reaching grassroots patients through an online survey. This information is now on its website. See www.euroguide.org.uk/

The EC funds and co-funds a wide range of projects that are health-related.

These projects can be very different. A project may be more (or less) medical or clinical. It may be closer to policy development or to the deployment of services. It may be more theoretical or it may be more applied.

In general, the projects that are co-funded by the EC are much wider in their concerns than purely research projects. The different types of projects which come under the umbrella of its co-funding cover a very wide scope including:

- Awareness-raising
- Capacity building
- Consultation
- Service delivery
- Fundamental research
- Clinical trials
- Research and development (including technological development)
- Policy (which of course includes health policy, but could also include research policy or technology policy).

Each of these different types of project will have its own set of aims and goals, will be of a different size and complexity, have different types of partners, and will have different levels of re-sourcing.

The **Salut** project developed Internet-based systems to improve diagnosis and services for eating disorders. Patients were involved in the process. Internet-based therapy is now available and in use. See www.salut-ed.org/index.php/

5.2.1 Selecting patient organisations and patients for the particular project

As a premise, it is useful to distinguish between involving patient organisations in projects, and involving individual patients. The two approaches are substantially different.

Being a patient is one side of the life experience of a particular human being. Patients can also bring the contributions and skills absorbed through their roles in life as parents, administrative or industrial workers, professionals, or people involved in their community, faith-based organisation or civic society.

Patients may be willing to be involved in a project precisely because of these specialist, professional skills, but most likely they will want to be involved because of the skills and knowledge they acquired by simply being patients and living with their condition. However, being involved in a project will not be a full-time job for them; project actors need to give considerations to this and other aspects explained in Chapter 6.

When considering a patient organisation as a project partner, the legitimacy, accountability, representativeness and transparency of that organisation are important elements. Who the patient representatives are, and how they are selected as a representative, are an important set of choices. They definitely need to be people who are competent to represent the official stance of their organisation with regard to the disease or condition at stake. The governance of the organisation is another aspect.

As a project co-ordinator and project leader, it can be worthwhile considering at an early stage of planning and preparation what kinds of relationships project partners have had in the past with patients and patient organisations and what kinds of relationships they would like to develop in the future. The questions below can help with this thinking.



They are purely 'starter questions' for a further set of concerns. Wider preoccupations will include: *what kinds of experiences related to patient involvement* people have had, *what their feelings* about those experiences might be, how all the partners involved could *seek to improve* circumstances and behaviours, and what *additional resources* and *policy improvements* can help to enhance the future experiences of patient involvement for anyone working in the project.

Many tools that are provided in the Value+ Toolkit can help project co-ordinators to move in this direction.

Considering how project partners might have interacted with patients and patient organisations in the past

- Are there project partners who are patients themselves?
- How many know about international, national, or organisational policies that offer guidance towards better patient-centred healthcare and patient involvement?
- Do the partner organisations have patient involvement policies?
- Have project partners had a professional or a policy-related relationship with patients? (They may for example be making local, national, or regional decisions that affect patients).
- Have project partners previously worked professionally with patients as patients, or with patients as colleagues?
- How many have only a 'literature-based' understanding of patients' needs?
- Do project partners run establishments that support patients (such as general practice managers, clinical managers, hospital managers)?
- Are project partners developing equipment or services that will be used by patients?
- How many develop publicity and public relations' materials for patients?

5.3 PROJECT STAGES AND PATIENT INVOLVEMENT

Projects have different stages. This set of stages is often called the project lifecycle.

A range of different interaction with and support to patient organisations and patients, might be needed in a project as it unfolds.

Projects co-funded by the EC usually involve the following stages:

- The Call for Proposals is launched, there is an 'expression of interest', and potential partners come together
- Proposal drafting and submission
- Evaluation process
- Negotiation meeting
- Project start or 'launch'
- The day-to-day running of the project
- Dissemination of a project's news, developments, and outcomes
- Project review(s)
- The project end.

The EC also encourages other kinds of initiative. These include public consultations, dedicated studies on very specific topics, and pieces of consultancy or policy guidance that support the work of the EC officials.

The Value+ Handbook concentrates only on European projects, and not on other forms of patient involvement. There are also many developments in patient involvement in projects at a national level with which a project co-ordinator or partners may want to get more associated. Some of these activities are very closely linked to patient involvement. Others are steps that can help patients become more motivated to get involved in collective issues affecting patients (e.g., working on their own care and treatment).

Other options which exist may involve:

- Strengthening patients' skills and capacities
- Learning-by-doing
- Getting patients involved in their own care and treatment
- Lobbying to improve patients' conditions
- Lobbying to enhance patient outcomes (prevention, treatment, recovery)
- Linking academics with health service users
- Influencing policy discourse and decisions.

During the course of the Value+ project, project co-ordinators often asked us a number of questions. They wanted to know:

- When (i.e., at what stage of the project) is it suitable to involve patients in European projects?
- In what activities is it most effective to involve patients?
- How is it possible to find patient partners or partner patient organisations?

This chapter talks about these questions at the appropriate stage in the project. It also deals with these kinds of issues in Chapter 6.

Patients, and patient organisations, can – and in many cases should – be involved at all stages of a project. This position was strongly supported by Value+ project members and by the patient representatives and patient organisations to which Value+ spoke.

These patients and their organisations may, of course, be different patients with different competences depending on the type of project which is under consideration, and the particular stage of the project.

As a general rule, an equal involvement between women and men at all stages of project development and implementation is more likely to add value to project outcomes.

Here are some examples of stages of projects and patient involvement. Some patients thought that particular stages of a project were more important than others. Among patients' suggestions for key stages of projects where they would wish to be involved are:

- Finding a proposal idea
- Drafting a proposal and submitting it
- Disseminating news about projects, and their developments and outcomes
- Keeping patients up-to-date about project outcomes.

To dedicate time, resources, and effort to this degree of patient involvement could mean that a project co-ordinator may consider it important for a project (or at its earlier stage, the project proposal) to dedicate a particular person to liaising with the patients or patient organisation. Chapter 6 of this handbook gives more detail of what may be required.

Of course, if the proposed project co-ordinator is a patient organisation, the organisation will also have to dedicate a particular person to liaise with patients.

Lastly, it may be that the liaison that occurs could simply be with a single person or patient. This will have its benefits (i.e., ease of contact with a single person). However, it may mean that a single individual or patient can become easily overloaded (just as all people may be overloaded if they are the sole person who is working on an initiative). Patients may, however, have particular challenges because of their health status; for example, they may experience chronic fatigue, and they may have regular medical appointments and treatment regimes.

5.3.1 Finding a proposal idea

To find an idea for a project proposal, project actors will need to monitor what ideas are coming up within the particular health-related domain of the EC, and know what the upcoming programmes and calls are.

Involving patients or a patient organisation at this stage, prior to submitting a proposal, usually requires a good knowledge about the landscape of patient organisations, and their organisational capacity and individual skills. More details on how to identify and approach patient organisations are provided in Chapter 6.

Calls for proposals, and their support information, need to be understood carefully and in detail. At this stage, it is important to be honest about the consortium's capacities and expectations in order to submit a credible proposal. A proposal based on a misunderstanding of the funding call, or aimed at a consortium's own interests in an attempt to fit pre-existing expectations rather than the call's objectives is unlikely to be successful.

It could well be that the patient involvement element of a project proposal is what makes the proposal special, different, and gives it particular value. Additionally, patient involvement in projects is highly likely to become an increasingly common characteristic.

A proposal idea should be formulated in a way that the added value of its patient involvement is apparent. What can this particular group contribute to the priorities and objectives formulated in the call text that another consortium will not be able to contribute? Involving a patient organisation or more than one patient organisation can indeed make a crucial difference here.



Clearly, here also, some consideration has to be given to how the various eligibility criteria would affect a patient organisation, how a patient organisation would comply with the application procedures needed to apply for an EC project, and how the organisation might match any necessary co-financing. This is an area where the organisation leading the project or the partners might have to provide support to enable the patient organisation to get on board in the project.

5.3.2 Proposal drafting and submission

It is important to make sure that a proposal matches very tightly the kind of work programme and the kind of call to which it is submitted. The EC tries, through the kinds of clear publicity that it gives to calls, to encourage submitters to put in only well-targeted proposals.

During the phase of proposal drafting, a project team needs to be tightly knit together, and for its members to be able to trust and rely on each other. There may be many discussions about competences, capacities, and resources. The proposal itself will need to undergo a careful drafting and writing process, and – almost certainly – be subject to very tight deadlines. Value+ has developed a ‘Capacity and Skills for an EC Project Checklist’ that can be used by all partners to identify what they can contribute to the project. The checklist is available in the Value+ Toolkit.

Involving patients or a patient organisation in this phase needs to be carefully planned. Like all partners, they will need to have a clearly pre-defined role and inputs.

As a potential partner, the patient organisation will of course be one of the parties to the agreement about the proposal planning and outline.

Like other partners, patient organisations may expect to take part in contributing to the whole project proposal. Indeed, there may be circumstances under which a patient organisation would contribute to all parts of a project proposal. If this is to be the case, the project co-ordinator leading this process may need to devote considerable care and attention to the patient organisation’s involvement all the way through the process. This will be necessary if the patient organisation does not have a long history of involvement in proposal writing; more interaction might be required to ensure appropriate content and quality of texts. This would involve not only resources, time, but also probably the direct attention of a particular person.

Often in reality, project partners contribute only to a specific part (or sometimes parts) of the drafting of a full project proposal. Of course, all partners may be encouraged to comment on a full draft proposal once it is ready. In this sense, a patient organisation would be no different in its involvement from any other project partner.

A good pre-condition for the involvement of a patient organisation is for it to be assigned to write a specific section in the proposal. The writing of this text will undoubtedly be where the patients’ special expertise about their condition and experiences comes in. It can contribute this part of the text once the overall outline of the proposal has been agreed or it may also, of course, be intensively involved in a discussion of the parts of the project in which it will be closely involved.

A proposal contains both a description of the intended project’s work and the accompanying administrative documents (which concern the legal and financial status of the consortium partners). Organisational professionalism is required of every project partner – including the patient organisation – in order to comply with these EC formalities.

This stage of proposal-writing can establish how partners will work together. From a patient organisation’s perspective, it is worthwhile encouraging involvement, and building relationships well before the proposal is thought of and designed.

A proposal, however, is usually written at high speed and within a very limited time-period. Different parts of a proposal can be written by a wide diversity of people. It is the project co-ordinator of the organisation leading the project who takes the ultimate responsibility to ensure that all the parts are brought together appropriately.

This means that the actual process of close working together may be subject to considerable pressures during the proposal drafting and submission. Often more attention is paid at the point of the project launch to “getting to know you” among all the partners, and with the patients or patient representatives. This may be as much because – at this stage of preparation – there are high risks that a proposal will not be successful.

The proposal submission date, and even its time on a particular day, is very carefully stipulated by the EC. It is crucial to comply with these details. All partners – including the patient organisation – should be made aware of the tightness of this deadline.

The resources dedicated to this preparation, planning, and time-period, should be seen as an investment for the future, but one which is costly (including financially) to all the potential partners involved since the EC does not provide funds for it.

The handbook is not intended to guarantee success in submitting proposals to the EC or in having these proposals accepted. Proposal submission, and success in getting projects accepted, can be a challenging and onerous procedure.

Agreeing on a project's objectives Wherever possible in health-related projects, patients or patient representatives should be involved in helping to stipulate the objectives of a project. Project objectives need to be closely aligned with the general objectives of the call for proposal or call for tender; however, there is still some leeway for a project consortium to fine-tune the objectives to match its particular vision.

Your objectives need to be SMART: specific, measurable, achievable, realistic and timely. If the patient organisation or patient involved in the proposed project has little experience of formulating objectives, a clear formulation of such objectives may be a process which needs even more time and resources than usual.

Generally, patients and patient organisations should be encouraged to understand their roles and be motivated by them. Indeed, when they have a stake in the formulation of a project's objectives, their commitment to the project as a whole is likely to be higher.

It is worthwhile remembering, even at this early stage of thinking, that – if a project is successful in submitting a proposal – all the partners should consider quickly what will be the means to maintain the outcomes of the project once it has ended. How would products be turned into services or into revenue-generating activities in the future? In some countries, projects are started up with the notion that they must become self-supporting e.g., at the end of a three-year period.

5.3.3 The evaluation process

During the time around the evaluation period of the proposal, and the time immediately following it, is important to manage the expectations of all partners to the proposal, including the patient organisation(s).

Partners have put a great deal of time and effort into creating the proposal. If the patient organisation applies regularly to EC funding, it will know that frequently it is not successful in its submissions. If it is new to the adventure, the organisations' members may be disappointed by the effort they have put in especially if the proposal receives a negative result.

Few proposals are successful, sometimes the ratio of success to failure is as high as 1:12 or 1:10. Sometimes proposals become successful after their third or fourth submission (providing that they are appropriately re-designed for a new call).

So far, health-related projects in the Directorate-General on Health have benefitted from a lower ratio of submission to acceptance: in 2007 and 2008, for example, as many as 1:5 or 1:4 health-related proposals were successful on submission.

In a time of socio-economic difficulty, it is likely there will be a growth in submission of proposals to the EC to do projects. Submission ratios may therefore climb even higher. Also, as publicity gets better, more people will submit. The evaluation process is fully in the hands of the EC. It cannot be influenced by any member of a project team, and no member of the team should try to exert any pressure in this way.

All partners including the patient organisation, and especially the project co-ordinator, will be keen to learn about the results of an evaluation. The results may take some time to materialise – from weeks to months, and in exceptional cases, may be even up to a year.

The results of the evaluation are communicated to the project co-ordinator. They highlight the strengths and the weaknesses of the proposal. It is the project co-ordinator's job to inform all the partners (including the patient organisation) of the result of the evaluation when the news is eventually received from the EC. It is likely that the patient organisation, just like all the other potential project partners, will be awaiting the results eagerly.

This next sub-section assumes that the proposal submission is a successful one. Congratulations to the success project proposers, including the patient organisation, on having gotten so far!



5.3.4 The negotiation meeting

The negotiation meeting is a critical moment for the development of any project. It means that the project proposal was successful as far as the evaluation is concerned.

Now, the proposal needs to be fine-tuned to take into account any comments that emerge from the evaluation, to meet the specific needs of the EC, and to comply with any reduction in budget. This will need to be done within a given timeframe (and will often be subject to tight deadlines).

Of course, no negotiation outcome is guaranteed. The eventual likelihood of the proposal being turned into a project depends on the success of the negotiations. This means that the project team will need to adapt its initial ideas to the suggestions made in the evaluation feedback, and to any requests made by the EC.

A negotiation can take place physically as a meeting, over the phone, or sometimes via email.

In the situation of a physical meeting, only the key partners of a potential project attend a negotiation meeting (they represent, for example, the project co-ordinator, the theoretical part of a project, the project management aspect of a project, its financial component, and possibly – if necessary – any legal component. In any case, the number of persons who attend such a meeting is generally quite small (e.g., 4-8).

Other partners usually give the project representatives, who are negotiating the project details, a mandate to negotiate on their behalf. Unless a patient organisation is a key partner in a project team, the presence of patient representatives is rather unlikely in this setting.

Of course, it may be that the patient component of a proposal is particularly strong or intensive, or that the evaluators have asked for any information about patients to be especially strengthened or defended. This may mean that the presence of a representative from a patient organisation or a patient may be especially welcome at a negotiation meeting.

When a patient organisation participates in a negotiation meeting, the project co-ordinator will need to work with the organisation (or the individual) to prepare the meeting carefully and to give appropriate input during the negotiation.

A negotiation meeting is likely to follow a specific schedule or agenda. The EC may be represented by several officials or only by one official. Mostly the content of the meeting will be formal and will concentrate on a set of key questions. It is also highly possible that a short PowerPoint presentation may be needed. Certainly, answers to the evaluators' questions and to specific questions or points raised by the EC will be needed.

It could be worthwhile, for all partners, including patient organisations, to rehearse with its representative any presentation of PowerPoint slides, the questions that may be asked and the answers to be given, and to talk in a very clear way about the way in which the meeting will be run.

Let us suppose that the negotiation phase is successful, and that all the revised technically-related and administratively-related paperwork has been submitted in due time.

A project generally starts in the month following the signature of all the official documentation and possibly even on the first day of the month following this signature. It is important to let the patient organisation, as one of the project partners, know this as soon as possible so that it can plan accordingly.

5.3.5 The project start or 'launch'

This is when the concrete activity of the project starts. It is important for a project team to take advantage of an early start and not to waste any time in starting up. This can, of course, be challenging if it is a holiday-period of the year. For patients, it could be especially challenging if it is a period when they are undergoing any form of treatment.

A critical step is the organisation of a first internal project meeting. It is important that, at this meeting, there is a further agreement among participants about the planning of the project work, the distribution of tasks, and important intermediate goals. The meeting should also clarify the administrative duties of each participants and how the co-ordinator will interact with each project participant.

This launch meeting is likely to be very important for the patient organisation in the project team. The launch meeting can provide an opportunity to build working relationships; some informal time or working in small groups may help with this. If a patient organisation and its member(s) cannot join the project at the launch meeting for any reason, it will be important to make them feel welcome at future meetings.

Once the project has started, a whole range of areas of involvement is possible for patients or patient organisations.

5.3.6 Day-to-day running of the project

Two important aspects of a project are decision-making and coordination of activities. One of the EC requirements is to have a sound management structure; this translates in practice into the establishment of a project Steering Group or Committee where all the partners are involved.

The main role of this body is to make decisions related to the project and to give guidance.

Patients and patient representatives should also be the owners of the processes in which they are involved. They should therefore be involved in the decision making related to the project as much as possible. At all times, they should be informed about the rationale behind actions which may sometimes be requested in a more directive tone by the co-ordinator.

All projects have a contractual commitment to produce work and deliverables as a result of documentation that will have been signed with the EC. There will be times when a more participative or collaborative style, that patients may desire, could not be feasible because of urgencies or other priorities in the work process.

With regard to the overall project coordination, a very important part of activities for a project co-ordinator leading the consortium in the day-to-day running of a project is the follow-up on actions agreed, the coordination of activities among partners, and the contact with the project's project officer.

Usually some project partners take the lead in coordinating a specific set of activities, in EC terminology that is called a work package. Due to the unique expertise patient organisations have, it could be worth assigning to them the lead of a work package that can benefit most from their competence. This can vary depending on the project.

Some projects set up advisory boards or users' interest groups. If a patient organisation or a patient does not have the capacity, resources or time to be involved in the whole project, this can be a good alternative to ensure some form of patient involvement. However, the project co-ordinator should be careful to be clear about the specific role and the expectations. Also, the patients and patient representatives involved in this function should receive appropriate resources and information to enable them to be in the loop and give input efficiently.

5.3.7 Dissemination of project news, developments, and outcomes

Dissemination is frequently a very important outcome for patients and their organisations.

Because patients and their representatives are experts on their own condition, they have awareness for how their conditions and diseases should be described and they have a particular credibility which should be used to communicate project results effectively. Patient organisations and patients may be involved in:

- Developing a project dissemination strategy
- Designing or drafting press releases or similar publications
- Proof reading and approving them
- Attending public meetings, conferences and seminars as representatives of the project.

Patient organisations may also be involved in simplifying the language used in projects so as to facilitate ordinary ('grassroots') patients' understanding of the project's messages, or 'translating' the words of various health professionals.

Sub-section 4.9 of the Value+ Toolkit highlights some tips that may encourage the meaningful involvement of patients in this kind of activity. 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. One project partner could take the responsibility for sending updates to the same patients on any developments – or lack of developments – following any lobbying activities.

The Value+ Toolkit warns, however, of tokenism: see sub-section 2.5.1 of the toolkit. It is important not to exploit patients and patient organisations or to use their images in a purely symbolic way.

Depending on the character of the project, it is evident that not all the patients or patient organisations involved in a project may be responsible for dissemination activities. Their levels and areas of involvement may be quite varied. They may be active in project domains which do not lend themselves to dissemination work.



5.3.8 Project reviews

A review of a project can be undertaken in a variety of ways during the project.

Project reviews generally occur every 12 to 18 months, depending on the actual duration of the project.

They may be handled either at a distance by an expert in his or her office (or home) or at a location specified by the EC.

Let us suppose that the project review is a physical one. Depending on where the relevant EC personnel are located, examples of locations could include either Luxembourg or Brussels. It could also be at some other place of convenience (e.g., before or after a conference or a workshop).

Depending on the kind of health-related project, a review could be held in a location that has a relationship with the specific condition or disease at stake. Examples could include, at a patient centre, a care home, a hospital, or – if a technology is being produced – at a research centre or hardware or software development centre. If the project is mainly about users, it could take place in the office of a non-governmental organisation or even in the office of a health ministry or authority.

Some considerations may include: Is the location easily accessible for the patients who will participate? Is special access, transportation, or equipment needed? If it takes place in the surroundings of another conference or workshop, are the physical conditions appropriate? If the review is held on-site in a health-related centre, how much will the review interrupt the centre's daily running? These issues will all need to be foreseen and careful planning will need to take place to accommodate them.

There can be great benefits about holding a review on-site in a health-related centre or somewhere that the patients can get to easily. It can give the reviewers a very concrete and targeted view of what the project is doing, how the patients are participating in the project, and what the patients are getting out of the project. If technology or equipment is to be seen by the reviewers, it may be that it will function more effectively on-site.

If the EC wishes to have the degree of patient involvement in the project assessed (or else some other aspect of the project which is important for the patient/patient organisation) it can be appropriate to have a patient representative or representatives present to answer specific questions. This could become an increasingly salient point as e.g., the degree of involvement of civil society is borne in mind in projects. Civil society involvement in projects is already a criterion for assessment at the end of some projects.

Because a review meeting is a formal meeting, and much depends on its outcomes for the successful continuation of a project, it is worthwhile spending considerable time understanding the formal procedure of the review, planning the PowerPoint (or verbal) presentations to be made, the types of questions that may be raised and the kinds of answers that can be given, and the meeting's timetable. A rehearsal can be useful. It will be especially appropriate to run through these procedures with all partners, including patient organisation partners.

There are other types of project review. For example, in projects that liaise with the Executive Agency for Health and Consumers, an independent reviewer (who may sometimes be called an "evaluator") can be assigned to the project throughout its duration. The reviewer may get the opportunity to comment both on the content created by the project but also how it is working (its process). The Value+ project trialled this sort of approach. It used its particular evaluator's comments to fine-tune and adapt the team's behaviour and activities as the project progressed.

In some areas of the EC, reviews may not take place at all – a project simply receives its financing and it runs until it has completed its tasks.

A project's final review is particularly important for the successful completion of the project, for the project and its partners to maintain their good reputation in the field, and for the project to receive all its planned-for funding.

Final reviews need to be taken seriously, are often intensive, and need considerable planning as well as follow-up.

A final review is often a more intensive version of the project reviews that the project partners may have experienced throughout its lifecycle.

Patients' views on the success of the project and its outcomes may be particularly influential at this point. Their ideas about how to progress further with dissemination and publicity for the project, and about how they themselves, and their organisation, may embrace the project results could be vital.

Patients who attend review meetings need to be well briefed and supported throughout the project's lifecycle. This is especially so for a final review.

5.3.9 The end of the project

A key phase of any project is its final stage. Here a project must show its success. It must also complete its administrative and financial responsibilities.

The end of a project will bring other aspects to the fore: the project team will have formed a relationship throughout the duration of the project.

What happens next, after the end of a project, may be a crucial issue for patients. Keeping patients informed about a project's outcomes is very important, so a project co-ordinator should ensure that happens.

In Value+ focus groups, patients sent strong messages that they want to know what a project's results are, what it achieved in terms of concrete results, what its implications are for future action or for possible policy. The EC generally has at least two expectations of its projects. First: the actual Member States in which the project has taken place must benefit from and use the results of a project. This may mean that patients need to look at what funding and support is available locally, regionally, and nationally to continue to implement the good work that has been developed inside their project. Second: the EC does not support further or repeats a particular project even when it has been highly successful. Thus, any new proposal to be submitted for more funding and resources needs to be innovative, dynamic, and cover new ground.

At this stage of the project – clearly, as well as all the way along the project – patient partners may develop ideas for what may happen 'next' or 'after the project'. These ideas need to be captured by all concerned. It is important to explore in what way they can be harnessed for the future.

It can often be a frustration for project partners including patients, that there is no obvious follow-up possible that can receive EC funding. This may be because policy orientations have changed, funding priorities have altered or moved in new directions, and/or that the current project forms part of a programme or initiative that is towards its end.

It is crucial to manage carefully the expectations of all project partners with regard to 'continuity' of any project, and not to oversell the possibilities.

Patient partners, in particular, need to understand clearly that financing is made to a project to support it until the end of the project but not to sustain it after its end. Patient organisations may be encouraged to develop ideas for how the project outcomes may be taken forward by them in an effective way.

When a project is closed formally, it is an important administrative phase. It does not usually involve effort from project partners apart from the project co-ordinator, provided that adequate financial and qualitative reports, and agreed deliverables, have been submitted.

The EC does have a right to check on project financing for a time-period up until five years after the end of a project. So all projects partners, patient organisations included, should keep their records for at least that length of time. Patient organisations that have little familiarity with the type of records to be kept should receive proper support by the project co-ordinator.

Working With Patient Organisations





Project co-ordinators told the Value+ project that they would like to have guidance on the tasks that patient organisations can carry out.

This chapter deals with the ways to identify and get in contact with patient organisations and patients who are living with a particular condition or disease. It goes on to look at some aspects of the actual experience of working with patient organisations and patients. It draws on observations made in the Value+ Toolkit, and also relates working with patient organisations to the Value+ Model of Meaningful Patient Involvement, referred to throughout this section simply as the Value+ Model. Finally, this chapter examines the sustainability challenges that face patient organisations.

6.1 BACKGROUND INFORMATION ON PATIENT ORGANISATIONS

The enthusiasm and motivation of patients and patient representatives have been strong features of all the Value+ focus groups and workshops. They may have different levels of knowledge, different skills, competencies and life experiences which they bring to patient involvement. Despite this diversity, patient representatives and patients have a shared commitment to improving the healthcare and social circumstances of patients. Patient organisations have been built up as a direct result of this shared commitment. They have been created by patients and their families who have come together to work for improvements in healthcare and treatment.

There are clearly many different kinds of patient organisations. They operate according to different type of constraints (organisational competences, financial capacities, and resources). The European Medicine Agency's (EMA) definition of a patient organisation can be found at www.emea.europa.eu/pdfs/human/pcwp/1461004en.pdf

Many – which are often well known at either international or national levels – were founded some years ago and have built up strong organisational foundations, members, and supporters. They may have consolidated their competences, budgets, and the way in which they organise their activities. They may have procedures for recruiting and managing volunteers. They may run useful courses and programmes. Although a comparatively young organisation, EPF falls into this category and has delivered capacity-building workshops for other patient organisations.

Other organisations can be much smaller. They may even be very local, based in regions, cities, or towns in a particular geographic location. They may be located in urban environments or they may also be in isolated regions or places. They may be based around a particular clinic, hospital, or hospice. In recent years patient organisations have formed from Internet groups.

Other forms of territoriality affect patient organisations. They may be based around representation for a particular condition or disease – whether this is a chronic condition or a rare disease.

Many patient organisations have the motivation and energy to look outside the boundaries of their own members' conditions and to work co-operatively with other patient organisations at national or international levels.

More and more patient organisations are becoming pan-European and even international in their orientations. They recognise that, although the ways of handling their condition may be very different in a range of countries, the conditions themselves are very similar. Patients are seeking increasingly to support each other, and offer each other information. There are greater opportunities to share information now using email and the Internet. An organisation like EPF is pan-European, with member organisations which incorporate many kinds of conditions and diseases.

Currently, organisations that receive EC co-financing through projects are expected to conform to certain organisational conditions and to be of a certain financial solidity. The criteria emphasised by the EC are generally those which would facilitate the organisation being a good organisational and financial partner in a prospective project. However a consortium might gain great benefits from the expertise of a less strong patient organisation, which could participate in a project with some support from its partners.

It is important to be aware of the kinds of constraints which patient organisations experience. As a result of the work it has undertaken, the Value+ project has made a recommendation to waive the current funding criteria for patient organisations. It would like to see an easing of the funding parameters. In its Policy Recommendations Value+ has said:

“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. ... Simplify application procedures and set up specific Calls for small-sized not-for profit organisations and other types of organisations that have limited capacity to meet eligibility criteria of current programmes.”

6.1.1 Choosing patients and patient organisations

When a project decides that it wants to involve patients, it should decide whether to recruit individual patients or whether to involve a patient organisation. If a patient organisation is to be involved, the project can be guided by the Value+ Model. This requires that patients or patient representatives should be involved at the beginning and throughout the project in planning and decision-making, and that strategies for supporting patient involvement are developed at the planning stage. Bringing a patient perspective into planning the project may lead to outcomes that other project partners would not have thought of, or considered possible. It may be difficult to involve individual patients at the planning stage, though a patient consultant could be asked to comment on the proposal.

It is important to understand that in English the term ‘representative’ can be used in two ways: someone who is chosen to represent others, or someone who is typical of a particular group of people. It is essential to be clear what kind of patient is needed. Is it a representative who will put forward the views of a group (e.g., with a specific condition or disease)? Or is it someone who is typical of a group but who will only speak about the condition or disease from his/her own position or set of views?

If your project wants a patient who puts forward views on behalf of a group, you should ensure that the person or organisation has a communication structure that will support the work you want. This person will then act as a representative of the patient organisation and of the patients that organisation represents.

The queries received by a patient organisation usually provide its representatives with a good overview of the issues that affect patients with a certain condition. A patient organisation also usually has an appropriate structure to spread relevant project information back out to grassroots patients.

If you want a patient who puts forward views based on their own experiences, you should ensure that experience is relevant to your task. Individual patients have deeper knowledge of their own condition, but may not always 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.

If patient organisations become involved, they may carry out the project by using only workers from their own organisation but they may also involve grassroots patients for some project tasks, on a paid or voluntary basis. These possibilities should be discussed at the planning stage. Good practice in representing patients is discussed in the Value+ Toolkit Section 2.4.1.

To ensure an appropriate mix of women and men among the patients and patient representatives in the project, project co-ordinators need to be aware of any official rules and regulations governing gender in European projects, how to apply these, and where to get access to any help or advice that they might need to understand and apply these.

Different European health-related projects often focus on a particular condition or disease. The conditions covered by the projects that the Value+ team investigated included: asthma, autism, cancer, cystic fibrosis, dementia, diabetes, eating disorders, headache, mental health conditions, migraine, multiple sclerosis, neuromuscular disorders, Parkinson’s disease, and rare eye diseases. Projects also focused on genetic testing and pharmacogenetics.

Patient organisations throughout Europe can be found by searching the European Patients’ Forum’s Directory of European and National Patient Organisations at www.eu-patient.eu/projects/valueplus/directory

Other sources of useful information about patient organisations can be obtained from organisations such as: health authorities, hospitals, clinics, and palliative care institutions/hospices, foundations/charitable bodies, research institutions and universities, and specific industrial companies or industry coalitions.



6.2 WORKING WITH PATIENTS AND PATIENT ORGANISATIONS IN A PROJECT

“Community organisations understand better the needs of the ‘in between’ people: people who are seeking treatment, trying to find alternatives to treatments, or who are disillusioned with current treatment options”.

Project co-ordinator interviewed by Value+

6.2.1 What supports patients to be involved in projects and what can incentivise them?

The answers to this question may seem to refer more to individual patients than to patient organisations. It is important to remember that individual patients are part of the membership of patient organisations, and elect the Board Members who make the decisions about their organisation. Members may well take part directly in important decisions, such as whether to form or join a project consortium in preparing a project proposal. This is part of the cultural difference between patient organisations and other partners.

There are several aspects of patient involvement that may affect the decision of patients or patient organisations to become involved. They include:

- Reducing the marginalisation that could relate to their condition or the group of patients to which they belong
- Being able to represent their patient group
- Personal contact and other support for involvement within the project
- Being kept up-to-date on treatments and research relating to the condition.

Patients may see patient involvement in a project as a means of reducing some form of marginalisation or stigma. Their motivations in getting involved in a health-related project can range from: improving healthcare, treatments and the way they are delivered, to reducing inequalities in treatments that are available. They place value on the subjective experience of the patient who is likely to understand the patterns and experience of his/her own condition best, and has experience of coping with the condition, or even with multiple conditions. Patient organisations have an important role in communicating this expertise and making policy makers and health professionals more sensitive to the needs of patient groups including those who are marginalised. This is a significant factor in their motivation to take part in projects.

Previous contacts with other organisations so that something is known about them when a project is suggested, are important to patient organisations.

Individual patients want to have a contact person to liaise with them, and to give feedback and support. For a project co-ordinator, your patient organisation partner may be the most appropriate candidate for this role, if this is geographically possible. The patient organisation should be asked to set aside an identified contact person for this role, which would include regular contact meetings with patients. This is fully described in the Value+ Toolkit sub-section 3.5.4. Sometimes group sessions with their patients could also be useful. Any patient organisation contact person probably also needs to have a designated person with whom they in turn can liaise, and who is located inside the project's co-ordination or management team.

If the project does not have a patient organisation partner, someone in the project's co-ordination or management team must take on the role of managing the involved patients. Recognising patients' other time commitments, and planning the timescale of the projects, to allow for these commitments is an important matter that needs to be planned into the structure of a project.

It is also important to provide sufficient resources for patient involvement in terms of payment, expenses, training, and patient-friendly information. Making a payment for work done, as well as for expenses incurred, can make it possible for more patients to be involved.

Project co-ordinators with whom Value+ worked recognised that good communication competencies are necessary for project managers. They suggested that the project documents should be translated into the language of each participant, because it is much easier to involve patients, or get them to comment on project results, if they receive the information in their own language.

It is always important to keep patients up-to-date and informed. Many of the patients whom Value+ interviewed felt that they had not been kept in the loop, and they had not understood the full picture of the project nor what it had gone on to achieve. As a project co-ordinator, it is good practice to ensure that any patient who participates in a project is kept informed about the project's news and developments. A means of collecting and sharing information on an ongoing basis with the patient organisation (and in turn with its patients) should be explored.

Acknowledging patients' work and its impact in any project reports, in publications, and at project events, is essential.

Projects working to the Value+ Model will ensure that patient organisations work with prospective project partners to:

- Take part in developing and costing the detailed plans for these (i.e. those involving patients 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.

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 organisation and grassroots patients after their involvement in the project has ended about the impact of the project results once the project ends.

6.2.2 Ethical issues that are important for patients

Value+ focus groups identified that ethical issues can be a challenge in projects. Making an application for ethical permission can be a complicated procedure. Ethical permission procedures are often aimed at health professionals who work with patients on their treatment and care, as in clinical trials. These are all issues about which health professionals should be informed and competent.

These procedures are often not designed for organisations that want to work with groups of patients or individual patients, with no clinical input into a person's treatment or care. The kinds of ethical issues that patients are concerned about are often not covered by official ethical permissions. Rather, patient organisations develop their own ethical checks, for example, when they are asked for assistance to recruit patients. In the toolkit, an example of a set of ethical checks designed by Asthma UK is included.

Especially when patients are involved in projects, a number of general ethical issues also need to be borne in mind. Patient organisations or patients may be more concerned about the ethics that relate to dignity, fairness, equity, and justice. Examples can include attributing tasks, funding, and selection of patients.

Patients have told Value+ that these kinds of issues are of concern to them

Partnership and equality: Both patients and project co-ordinators considered these to be the core of good practice in patient involvement. Payment of individual patients for their involvement tasks is an equality issue.

Attribution of tasks: It is worthwhile paying attention to how to distribute tasks to different patients. Task should also be correctly remunerated.

Equity: It is crucial to avoid any type of discrimination in patient participation (examples can include race, religion, age, disability, gender).

Funding: Choosing appropriate funding sources, and ensuring transparency and independence in relation to those sources.

Selection of patients: Representatives should really represent patients.

Patients may also be very aware and sensitive to issues that relate to their privacy and confidentiality, safety, security, and consent.



Some health professionals may resist patient involvement in projects. One reason that they may do this, it has been suggested, is that they are confused about how to apply their own organisations' or occupations' ethical codes to patients who become their work colleagues, rather than people whom they treat. Some patients may be playing dual roles i.e., acting as both a work colleague and a patient, and both the patient and the health professionals may have to learn to handle this. Part of managing the health professional-patient or the patient-health professional relationship is about being really clear where micro-level personal healthcare stops and more macro-level patient involvement begins.

6.2.3 Patients' social and medical contexts

It is important to know about and understand the different social environments and medical conditions of patients involved in projects. This observation is meant in both an intellectual sense and also in terms of organising the research to benefit most effectively from patients' strong points. This should be framed with the dignity, respect and rights of the patients in mind. It should respect the relevant legal and policy instruments, and good practice with regard to ethics and confidentiality.

On the social side, it is also important to be aware of the differences between patients themselves and the needs of others. Other people associated with the involvement of patients may include: family members, carers, and advocates (e.g., people employed to advocate with persons who have a disability or a mental health condition).

On the medical side, it is important to know broadly about an individual patient's medical environment so as to understand what the person can do inside the project. Included here is the need to be aware of the issues connected with a particular condition, the availability of a specific patient, his/her capacities or skills, and his/her transportation needs.

For information about medical conditions, see Annex 3 of this handbook.

6.3 THE SUSTAINABILITY OF PATIENT INVOLVEMENT THROUGHOUT A PROJECT

European projects in health-related areas that aim to involve patients may face a number of challenges, particularly with regard to capacity and capacity-building.

The Value+ project has hoped to ensure that patients and patient organisations are involved throughout the duration of any given EC co-funded health-related project.

The different stages that are evident in the life of a project are numerous. In sub-section 5.3 of this handbook, it can be seen that the stages that come prior to the actual start of a project include: proposal drafting and submission, an evaluation process, and a negotiation meeting. Once a project has started, the stages constitute a project start or 'launch' – which is often a meeting in its own right, the day-to-day running of the project, project reviews, dissemination of a project's activities, work, and outcomes, and the project end.

It is absolutely possible and indeed desirable to involve patient organisations in all these stages. The Value+ Model covers all these stages, as well as evaluating the impact of the project after it has ended. Patient organisations may prioritise involvement in the actual proposal formulation and design, assuring themselves that the planned involvement is adequately resourced and that project outcomes are geared closely to patient needs and can feed effectively into policy. Patient organisations also have particular skills for communication with grassroots patients, ensuring that the documentation, publications and ideas that are to go out to patients can be easily understood by those patients, and are worded appropriately.

Various capacity challenges may be faced by patient organisations, and indeed other partners, at each stage of a project. One common challenge throughout the lifetime of any project is the patient organisation's own ongoing funding; few if any patient organisations receive guaranteed funding from national or local government and so they depend on their own fundraising efforts. As staffing is often the largest part of a patient organisation's budget, a temporary funding gap could mean that workers with valuable experience and expertise are lost to the organisation.

Financial challenges during a project could especially hit at such stages as: potential overspending of any budget at the start of a project when EC co-funding might be received *en bloc*. Another sensitive period may be towards the project end, when such a project partner may find it difficult to finance its activities. A patient organisation may find it difficult to ask for attendance and activity throughout the whole project from patients who are volunteers, quite apart from issues relating to the stage and severity of any condition they might be experiencing. Many mechanisms on how to deal with such situations are outlined in the toolkit.

6.3.1 Financing and resourcing patient involvement

Good quality patient involvement requires funding. A lack of funding may limit the degree of patient involvement. Involving patients and patient organisations well takes time and resources. When project partners have a commitment to patient involvement, they need to allow for these issues in the project planning. Involvement on the part of patients is often a voluntary activity rather than a full-time job, although in general, payment should be budgeted for long-term time-intensive tasks. Patients may need longer than other people who are working in a project to fit in a particular task. This can be because of their paid employment commitments, treatment schedules, or other personal circumstances. Appropriate time should also be made available when patient representatives need to organise two-way communication with grassroots patients to complete a task. This is especially so when grassroots patients do not use email, for example. Daytime meetings can also be difficult for patients who are working.

It is important for project co-ordinators to have a sound sense of the number of financial challenges that may face them, their projects, and their patient partners, even at the stage of preparing a project proposal.

Today, many patient organisations see European project eligibility criteria as very complex. Project co-ordinators might think carefully therefore about how some level of waiving of co-financing procedures and simplification of application procedures might be beneficial to patient organisations, and how patient organisations might benefit from greater access to funds at both European and national levels. Patient organisations might also benefit from having specific contact points or persons. Evidently, these are also highly appropriate considerations for EC and European agencies' officials.

Annexes



ANNEX 1 - READING MATERIALS

This annex contains some useful reading materials that relate to the main topics covered by meaningful patient involvement in projects. The materials are in different languages, not simply in English.

PATIENT INVOLVEMENT

Publications

Arstein, SR (1971) A ladder of citizen participation. *Journal of the Royal Town Planning Institute*: 2-6

Bagott, R; Forster, R. Health consumer and patients' organizations in Europe: towards a comparative analysis. *Health Expectations*:11:85-94

Bericht des Ausschusses für Bildung, Forschung und Technikfolgenabschätzung (18. Ausschuss) gemäß § 56a der Geschäftsordnung Technikfolgenabschätzung (TA) *Zukunftsreport Individualisierte Medizin und Gesundheitssystem*. Bundestagsdrucksache 16/12000, dated Feb-ruary 17th, 2009

COM(2008) 414 final 2008/0142 (COD) *Proposal for a Directive of the European Parliament and of the Council on the application of patients' rights in cross-border healthcare*

Coulter A, Parsons S, Askham J (2008) *Where are the patients in decision-making about their own care?* policy brief written for the WHO European Ministerial Conference on Health Systems, 25-27 June 2008, Tallinn, Estonia

De Gooijer W (2007) *Trends in EU Healthcare Systems* New York: Springer

Directive 2006/123/EC (2006) Directive on services in the internal market <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2006:376:0036:0068:EN:PDF> See L376/36 Official Journal of the European Union. 27.12.2006

European Council (2006). *Council Conclusions on Common values and principles in European Union Health Systems*. Brussels, European Publications Office. C 146: 1-3

Goodrich J and Cornwell J (2008) *Seeing the Person in the Patient: The Point of Care review paper*. London: The King's Fund ISBN 978 1 85717 577 6

Hart D (2004) Patients' rights and patients' participation individual and collective involvement: partnership and participation in health law. *European Journal of Health Law*,11:17-28

Hofmarcher MM and Rack HM (2006) *Austria: Health System Review, Health Systems in Transition* 8(3): 1-247, edited by Riesberg A, European Observatory on Health Systems and Policies

Leys M, Reyntens S, Gobert M (2007) *La participation des patients dans la politique des soins de santé: revue de la littérature et des initiatives internationales et belges*. Bruxelles: Fondation Roi Baudouin ISBN-13:978-2-87212-526-5 www.kbs-frb.be

Naidith, N. Patient organizations and public health. *European Journal of Public Health* 17(6):543-545
Richards, T (1999) *BMJ*. 318:1234 (May 8, 1999) www.bmj.com/cgi/content/extract/318/7193/1234/b

Tritter J, Koivusalo M, Ollila E, Dorfman P (2009) *Globalisation, Markets and Healthcare Policy. Redrawing the Patient as Consumer*. London: Routledge

WHO (1999) *Patients' Rights and Citizens' Empowerment: through Visions to Reality* Joint consultation between the WHO Regional Office for Europe, the Nordic Council of Ministers and the Nordic School of Public Health Copenhagen, Denmark 22-23 April 1999

Websites

Shaping our Lives, national user network (United Kingdom) www.shapingourlives.org.uk/

"Your guide to the NHS. Getting the most out from your National Health Service" (2001) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007349

International Alliance of Patients' Organizations, Guidelines on Patient Involvement www.patientsorganizations.org/attach.pl/591/184/IAPO%20Guidelines%20for%20Patient%20Involvement.pdf

Involve is an England Department of Health-funded national advisory group for public and patient involvement in England's national health service. It has useful guidelines for funders and researchers, including:

- Good practice in active public involvement in research
- A Guide to Actively Involving Young People in Research: for researchers, research commissioners, and managers
- Peer reviewing research proposals: guidelines for members of the public. A series of seven guidelines to help commissioners, researchers and the public to think about public involvement in research commissioning.

www.invo.org.uk/

USER RESEARCHERS

User researchers or survivors, and health professionals, have all written chapters in this book which was published in 2009:

Wallcraft J, Schrank B, and Amering M. (2009) *Handbook of Service User Involvement in Mental Health Research*. Chichester, UK: Wiley-Blackwell ISBN 978-0-470-99795-6.

This 2009 book was written entirely by user researchers or survivors:

Sweeney A, Beresford P, Faulkner A, Nettle M, and Rose D (2009) *This is Survivor Research*. Hay-on-Wye, UK: PCCS Books ISBN 978-1-906254-14-8

GENDER IN RELATION TO HEALTH

Here is a list of books and articles published over the past decade which are relevant to the notion of gender in health-related projects:

Branney, P, White, AK (2008) Big boys don't cry: men and depression. *Advances in Psychiatric Treatment* 14: 256–262

European Commission (2006) 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 and Dinant, G (2007) Integrating a gender dimension into osteoporosis and fracture risk research. *Gender Medicine* 4 (supp B) S147-161

Klinge, I (2008) Gender perspectives in European Research. *Pharmacological Research* doi:10.1016/j.phrs.2008.08.011

Lesley L (2008) Women's interpretation of cardiac symptoms. *European Journal of Cardiovascular Nursing* 7(3): 161-162

Oliffe J and Mrocz L (2005) Men interviewing men about health and illness: ten lessons learned; *Journal of Men's Health* Vol. 2, No. 2, pp. 257–260, June 2005

Sen, H and Östlin, P (eds) (2009) *Gender Equity in Health. The Shifting Frontiers of Evidence and Action*. Routledge ISBN: 978-0-415-80190-4

Vidal C, (2006) Neurobiologist, Institut Pasteur, Paris, France, 'Brain, sex and ideology' in *Talking Life to both Sexes*, European Commission conference report, sec 1:9, February 2006

Wizemann T.M. and Pardue M-L. (2001) *Exploring the biological contributions to human health: does sex matter?* Washington, D.C.: Institute of Medicine.



ANNEX 2 – EXAMPLES OF GOOD PRACTICE

This annex provides a brief description of projects with examples of good practice that were selected by the Value+ project team.

Illustrations and pull quotes from these projects have been used as examples particularly in the toolkit but also in this handbook.

The range of projects used demonstrates the wide variety of activities in which patients and patient organisations can become involved.

All these projects were supported by EC co-funding, unless the description states otherwise. The projects are categorised under broad activities that projects that are health-related might be inclined to undertake.

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 any 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

PROJECTS WITH PATIENT ORGANISATIONS 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 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/~extranet/>
- 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/
- The Mental Health Europe project '**Good Practices for Combating Social Exclusion of People with Mental Health Problems**' included mental health organisations from 10 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. This information is available on a website, 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 10 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. This information is now on their project website, 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. Selfhelp 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 health care, 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/

ANNEX 3 - WHERE TO FIND OUT MORE ABOUT PATIENT ORGANISATIONS, PATIENTS' CONDITIONS, AND PATIENTS' RIGHTS

This annex contains country-specific information covering all the Member States in the European Union. It is not however fully comprehensive.

There are web links to sources where to find lists of patient organisations, people or organisations with patient involvement experience, descriptions of patients' conditions and legislation or regulation on patients' rights in individual European countries.

Patient organisations

EPF has developed a directory of European and national patient organisations. Most of them are disease-specific while some address broader issues related to patients. The directory can be accessed at www.eu-patient.eu/projects/valueplus/directory

Value+ developed a database of all the projects that were the object of its assessment on patient involvement in EC health-related projects. All the projects were included although it was not possible to assess precisely if and how they involved patients and patient organisations. Value+ thought it would be useful to include them all in case the readers want to do further research on any of them.

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

Patients' conditions

Details with regard to the specific conditions and diseases that patients who are involved in a project are experiencing could be useful information for project co-ordinators. A useful link is England's NHS Direct which has a "Health A-Z". For every letter of the alphabet, it gives succinct information on the symptoms of many different conditions and diseases (in some cases, there may be up to one hundred conditions per letter of the alphabet)

www.nhs.uk/Conditions/Pages/bodymap.aspx?r=1&title=Health+Encyclopaedia

Patients' rights in the EU

EPF compiled an overview of patients' rights in the European Union. It describes the specific legislative framework in each Member State: www.eu-patient.eu/projects/valueplus/resources/attached_documents/overview-of-patients-rights-in-the-member-states.pdf

Further sources are:

http://europatientrights.eu/about_us.html

The European Charter of Patients' Rights by the Active Citizenship Network:

www.activecitizenship.net/content/blogcategory/32/77/

'The patients' charter and you a charter for England' (1991): www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006022



ANNEX 4 - VALUE+ TOOLS

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.

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:			

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 – 'ticking the box' 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.

Glossary



GLOSSARY OF TERMS

Some readers of the handbook will be new to European projects. Therefore, whenever terms that are obscure or unusual are used in the handbook they were underlined. A full description of the underlined words is located in this glossary of terms.

Readers can also look at the glossary entries in the companion Value+ Toolkit.

The EC and its executive agency for public health have their own terminology for referring to projects. It is always the Commission's official definitions or descriptions that represent the formal, accepted ways of referring to project matters.

All project co-ordinators, whether actual or potential, need to make themselves familiar with these terms. It is the official vocabulary that they will need to use whenever they are involved in making proposals for European projects or in coordinating actual projects.

The short descriptions that are provided in the glossary are never meant to replace any official EC explanations.

Sources of definitions

Some of the sources of the definitions outlined in the glossary include:

CORDIS - The Community Research and Development Information Service (CORDIS) of the European Commission provides an English language glossary of terms:
http://cordis.europa.eu/guidance/glossary_en.html

DBIS - The United Kingdom's Department of Business Innovation & Skills (DBIS), Project Centre glossary of terms:
<http://www.berr.gov.uk/aboutus/corporate/projectcentre/glossary/page10895.html> Accessed 24/09/2009

The Executive Agency for Public Health
<http://ec.europa.eu/eahc/> Accessed 11/11/2009

The New Oxford Dictionary of English (1998)

Glossary entries

Associated partner – An associated partner participates in the project on the same basis as the main partner in the project. It has a contractual relationship with the agency responsible for the contract

Benefits basket – The benefit basket refers to the totality of services, activities, and goods covered by publicly funded statutory/mandatory insurance schemes (social health insurance, SHI) or by National Health Services (NHS)

Call for proposals – The different Directorates-General (DG) of the EC have programmes that finance projects. The announcement of possibilities for financing is a “call for proposals” that explain the topics, eligibility criteria, procedures and deadlines to submit project proposals. Calls are launched at various intervals during the year depending on the DG

Capacity-building – Improving the skills of people so as to extend the activities in which they can take part

Case study – A process or record of research in which detailed consideration is given to the development of a particular person, group or situation over time

Checklist – A list of items required, things to be done, or points to be considered, used as a reminder

Civil society – Is composed of all the voluntary civic (i.e. related to citizens) and social organisations and institutions that form the basis of a functioning society as opposed to the structures of the state and of commercial institutions. Civil societies are often populated by organisations such as registered charities, development non-governmental organisations, community groups, women's organisations, faith-based organisations, professional associations, trade unions, selfhelp groups, social movements, business associations, coalitions and advocacy groups

Co-funded (also co-financed) – A co-funded project is one that is paid for by both the EC and the project partners that are carrying out the work. The funding from other sources will need to make up the difference between one funder's contribution and the total cost of the activity

Co-financed – See co-funded

Collaborating partner – A collaborating partner is a member of a project consortium that offers its collaboration but does not participate in the project on an active day-to-day basis, is not contractually bound to the project, and does not receive any form of funding from the EC. It provides added value to the project and participates in the project together alongside the main and associated partners

Complementarity – The interrelation of reciprocity whereby one thing supplements or depends on the other

Consortium – A group of organisations which joins together for a specific purpose. In an EC context, these are the partners in a project. In this handbook, we often refer to them as a 'project team' or 'team'

Consultation – A technique of social interaction where opinions of all stakeholders are sought before a decision is made

Database – A structured set of data held in a computer, especially one that is accessible in various ways

Deliverable – A thing to be provided, especially as a product of a development process. An end product of a project or the measurable result of an intermediate activity

DG SANCO – See Directorate General for Health and Consumers

Directorate-General (DG) – A department of the EC responsible for a particular policy area. Examples currently include health, employment, enterprise, information technology, justice and law

Directorate General for Health and Consumers – DG SANCO aims to make Europe's citizens healthier, safer and more confident. The European Union has established laws on the safety of food and other products, on consumers' rights and on the protection of people's health. It is the responsibility of national, regional or local governments in EU countries to apply the EU's health and consumer protection laws. The Directorate General for Health and Consumers ensures that the laws are applied properly in each country, and to keep the Europe-wide legislation relevant and up-to-date. http://ec.europa.eu/dgs/health_consumer/index_en.htm

Dissemination – In an EC context, it 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

Field research – Generally considered to be research or study that takes place in a non-laboratory or non-academic setting, i.e., done "in the field". Its historical background comes from anthropology and ethnography. Examples of field research include participant observation and less formal means of data collection and survey research

Gender – This term refers to the activities, attributes, behaviours and roles that a given society considers appropriate for men and women. This distinguishes between male and female on the basis of cultural and social differences. See also sex

Governance – The combination of processes and structures implemented by the Board (consisting of representatives elected by the organisation membership) of an organisation to inform, direct, manage, and monitor the activities of the organisation toward the achievement of its objectives

Health literacy – "Health Literacy is the ability to make sound health decisions in the context of every-day life – at home, in the community, at the workplace, in the health care system, the market place and the political arena" is used in Kickbusch, I., Wait S., Maag, D. (2005) *Navigating Health: The Role of Health Literacy*. London: Alliance for Health and the Future, International Longevity Centre-UK. www.ilonakickbusch.com/health-literacy/NavigatingHealth.pdf. From a patient's perspective, the knowledge and competence gained through health literacy lead to the strength and empowerment needed to manage well a disease/condition and its impacts on quality of life

Health-related – This term is used to indicate projects that in some form or another are related to health. It could be projects focusing on advocacy on health, clinical trials, health education or development of technologies

How to – Is an informal, often short, description of how to accomplish some specific task

Lifecycle – See project lifecycle

Macro-level – The overall, general or large-scale level of a concept or process. In social work, the macro-level involves society or communities as a whole. This type of social work practice would include policy forming and advocacy on a national or international scale.

Micro-level – Focuses on individuals and their interactions. In social work, it involves service to individuals and families



Member State – A Member State of the European Union is any one of the 27 sovereign states that have acceded to the European Union (EU) since its de facto inception in 1951 as the European Coal and Steel Community, http://en.wikipedia.org/wiki/Member_State_of_the_European_Union

Outcome – The way a thing turns out; a consequence. In a project, it can be equated with the project results

Patient involvement – It 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 organisation – A not-for-profit non-governmental organisation (NGO). Its members are patients with a particular condition or their informal, unpaid carers, that is, friends and family

Peer review – This is a process used in the academic or scientific environments in which the work of one researcher is subject to impartial (and often anonymous) criticism and review by other appropriately-qualified researchers. It is sometimes also called refereeing. It is almost always used before an academic or scientific article is published, and especially in academic journals

Policy officer – An EC project officer who focuses on policy. Note that this may be health policy or it may equally well be another example of policy such as education and training policy, employment policy, research policy, telecommunications or technology policy

Process-related – It refers to a series of actions, changes, or functions bringing about a result. It focuses more on these actions than on the results

Project actors – It is the collective definition used in this handbook for project co-ordinator, project leader and project promoter

Project co-ordinator – In this handbook a project co-ordinator is a staff member in charge of managing a project within an organisation

Project leader – According to this handbook is the organisation which leads the consortium implementing a project

Project life cycle – A sequence of defined stages over the full duration of a project

Project officer – An EC official appointed to act as the contact-point for the project in all matters that affect the EC

Project promoter – Is an organisation or an individual promoting politically or financially a project without necessarily being involved in its implementation

Project 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

Project team – The people responsible as a whole for carrying out project tasks

Pull quote – A quote from an article or paper (in our case, from the text itself or interviews, focus groups, or projects that highlights a key topic around meaningful patient involvement in health-related projects). It is a term that is often used in journalism or publishing. Most people see pull quotes used in the newspapers or magazines that they read

Reference book – This is a collection of information that is usually of a specific type, and compiled in a book for easy reference. The information is intended to be found quickly when needed. A reference work is usually made reference to for particular pieces of information rather than to be read cover to cover. The writing style used in a work of this sort is informative. The use of the first person is avoided, and facts are emphasised

Sex – Either of two the main categories (male and female) into which humans are divided on the basis of their reproductive functions. This distinguishes between male and female on the basis of biological differences. See also gender.

Scientific officer – An EC project officer who focuses on science

Stakeholder(s) – Someone who has an interest in a particular issue or decision

Survey – An investigation of the opinions or experiences of a group of people, based on a series of questions

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

Toolkit – A kit of this sort contains a set of tools (models, methods, and techniques). In the case of Value+, the tools contained in the toolkit are ones that patient organisations and patients may use to facilitate their involvement in a European project, and from which project co-ordinators may get a good sense of what meaningful patient involvement is about

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

Work programme – The programme of a specific DG. It has an average duration of 5-7 years.



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”

PROJECT LEADER



ASSOCIATED PARTNERS



COLLABORATING PARTNERS

