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## Values and Criteria of People with a Chronic Illness or Disability

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## SUMMARY

# VALUES AND CRITERIA OF PEOPLE WITH A CHRONIC ILLNESS OR DISABILITY

**Strengthening the voice of their representatives in the health debate and the decision making process.**

## INTRODUCTION

The number of people in the Netherlands with an illness or disability is on the rise, and the same trend is also observed in many other European and non-Western countries. This expanding group of people has experience and knowledge about what it means to live with chronic illness or disability and about the consequences for themselves, their immediate environment and for society. This knowledge and experience, usually accumulated over the years, and in many cases in interaction with professional and even scientific knowledge, is generally referred to as experiential knowledge.

With their experience and knowledge of their fellow members, representatives of people with chronic illness or disability are increasingly serving as partners in the health debate and in negotiations on health care and research. The idea behind this is that the quality of health projects improves, e.g. on guidelines or scientific research, is a better reflection of their voice, and what these people contribute leads to a much more complete picture. Moreover, this is a normative ideal involvement in quality and research and gives voice to those to whom it applies: people with a chronic illness or disability.

To date little is known about how representatives of people with a chronic illness or disability experience their involvement activities. Criteria are not existing or incomplete and people are not fully aware of the issues that matter to their peer group. Not clear, for example, are the criteria on which their appraisals of research and care should be based.

The purpose of this study is to investigate what constitutes experiential knowledge of people with a chronic illness or a disability, and how their issues are and can be used in involvement practices by their representatives. Three aspects need to be addressed. First it is important to investigate what matters to the people, and what are shared issues of concern. Second, it is crucial to investigate what criteria representatives use to appraise care and research from a patient perspective. Third in which way representatives can put these matters on the table in the interaction with professionals. All this does not relate to the individual patient-caregiver interaction nor to individual experiential knowledge but to

the widely shared experiences and opinions of people with a chronic illness or disability on a collective level. This leads to the main research question for this thesis:

*What constitutes the body of experiential knowledge of people with a chronic illness or disability in the context of appraising quality of care and research ?*

Together with these people, and based on this assessment and knowledge, we developed appraisal criteria to be used by their representatives who assess and evaluate on their behalf. This will give them something to hold on to and hence more support when they are at the table with scientists, policymakers, managers, care professionals and the many other discussion partners they meet during review processes and in the debate in general. This means that the values and issues of the individual members of their peer group can be put forward more effectively.

To this end we examine the following in this study :

1. *What matters to people with a chronic illness or disability concerning research and quality of care?*
2. *According to which criteria do representatives of people with a chronic illness or disability appraise research and quality of care?*
3. *How do representatives of people with a chronic illness or disability and professionals interact and relate to each other during involvement activities?*

This study examines the involvement of advocates and involvement of groups, and the widely shared experiential knowledge of people with a chronic illness or disability that are put forward in the health debate and decision-making processes in research for them, or on their behalf.

## **THEORETICAL FRAMEWORK**

We assume in this study a theoretical conceptual framework based on the following concepts:

***Experiential knowledge:*** ideas, experience and knowledge from the environment in which people live their lives, can contribute to better research and improve the quality of care. Scientific research and guideline development are processes derived from science-based principles and criteria, and are 'evidence based'.

Experiences or principles based on practical experience; usually referred to as 'practice-based ', hardly ever play a role in traditional scientific knowledge and guideline development. There is in fact disparity when comparing or appreciating the two fields of scientific knowledge and experiential knowledge.

The main characteristic of experiential knowledge is that it is practically relevant and applicable. Experiences become experiential knowledge as soon as they are recognized by a larger group of people with a chronic illness or disability. Experiential experts would also have the capacity or ability to learn to reflect on their experiences and knowledge, and to be able to view them from multiple angles and identify with stories of fellow peer group members.

Involvement of people with a chronic illness or disability is largely based on their experiential knowledge. The concept behind experiential knowledge is that ideas, experience and knowledge of those with an illness or disability covers all aspects of their life, is intertwined with the illness or disability concerned and comes from the environment where people lead their life.

Involvement in for instance guideline development is justified because issues from this personal life-world environment are very different from issues important in the scientific and professional environment. Additionally the concept assumes that interaction between the two environments is both possible and necessary.

**Partnership:** the experiences of people with a chronic illness or disability are a source of experiential knowledge and are used in decision-making processes. A second prerequisite is that these people are seen as *equal partners* in the knowledge acquisition process. They are actively and equally involved in the development, implementation and evaluation of the research, the quality of care projects and policies. There are several parties in the dialogue all with differences and similarities in their views and perspectives. The idea is that all parties in an on-going dialogue develop mutual understanding of each other's positions, thereby enabling new opportunities and ideas.

When a specific group of people are barely involved at all in participation practice, or do not actively participate or truly join in with discussions on a major activity, then what we are looking at is non- or pseudo-participation. Ideas about commitment, equality, equal rights, equal opportunities and being heard are all closely linked. Involvement and participation are often cited as the opposite of exclusion, which is about more than just a lack of participation in decision-making processes. Whether or not to participate in society is directly related to groups of people who, in one way or another, are behind or disadvantaged and marginalized in society. Participation and empowerment are closely linked.

**Responsive research design and research methods:** This thesis follows a responsive research design approach in which an inventory of the issues of different stakeholders (people both interested in the study and important to the study) were assembled and compared for comparison. An attempt was made to establish the issues and their value and meaning, by means of a common search strategy together with stakeholders. The idea is that mutual understanding between stakeholders is, in itself, a requirement for achieving improvements in practice. Various research methods were used to identify, elaborate and exchange issues and values among stakeholders and in a dialogue with researchers.

Firstly, an auto-ethnographic research type based the story of Truus, the first author, who lives with multiple chronic diseases, is reported on in Chapter 2. The research method used is a narrative data collection and analysis and was conducted in order to record and analyse the experiences, feelings and events in her life with multiple diseases.

In Chapter 3 we present a qualitative exploratory research type to get an idea of the experience, important issues and values of people with chronic illness or disability in practice. As method we drew up a content analysis of relevant documents, and interviews were held and analysed and participant observations performed. Areas outside traditional medical science were also examined to find those issues relevant to people with chronic illness or disability.

Chapter 4 describes a literature review type study to identify subjects and values of people with chronic illness or disability as they are currently identified by science. International scientific literature and content analysis was carried out as research method. In addition to the search in primary (scientific sources) literature, information was also collected to this end from secondary and tertiary sources (databases of organisations of people with chronic illness or disability, non-scientific publications, reports and information).

The research type we used in chapter 5 is a qualitative type study and as a research method we used in-depth interviews, telephone interviews and focus groups. Also we used content analysis thematic analysis en data syntheses. Focus groups were held to find out which topics are important for people with chronic illness or disability. These issues were analysed and then combined into a set of criteria that was discussed, revised and prioritized by the people themselves in a series of focus groups, roundtable discussions and interviews. This was done repeatedly with different participants each time.

In chapter 6 we use three different research methods, all of the qualitative research type. The chapter presents three studies that describe the participation of people with chronic lung disease. Section 6.1 presents a longitudinal case study with document search, interviews and observations and a time cross section analysis. We investigate how and to what extent lung patients participated over the past 7 years in Lung Foundation Netherlands (LFN) funded lung research. Section 6.2 we use a qualitative study as a research method and we use questionnaires, interviews and focus groups for data collection and content analysis for the data analysis. We examine how the LFN sets the research agenda together with people with a lung disease. Section 6.3 uses also a qualitative study as a research method with in-depth interviews for data collection and content analysis to analyse the data. We investigate shared responsibilities and involvement in the practice of people with Chronic Obstructive Pulmonary Disease (COPD) and their caregivers, via an interactive method.

## A COUNTER STORY

The author's search and the questions that gave rise to this research and thesis are presented in Chapter 2 about "struggling between strength and vulnerability, a patient's counter-story". Living with multiple chronic diseases and disabilities, she describes her 27 year' struggle from the moment she became ill to the present. This led to a counter-story based on a number of critical moments in her life. Her struggle with strength and vulnerability exposed another side to people with illness or disability, which contrasts with the articulate, independent patient that is increasingly talked of in health care. The prevailing image is that of sturdy citizens whose own choices and control of their life are firmly in their own hands.

This story shows that things are not that simple: the patient will experience everything between strength and vulnerability, and between constraints and opportunities. Recurrent episodes of loss and mourning, and development and growth alternate with each other. People with a chronic illness or disability can be fully occupied merely by their basic needs and physical survival. This may involve work, attending courses or school, having to stop a hobby, cancelling an appointment with friends yet again, or constraints to the support they can give to their peer group – and all have major implications for them to have their say in processes and participation in society.

At any given time a reversal may need to be recognized in the life of someone with an illness or disability: renewed growth, and an opportunity to focus on the immediate environment. Particularly important is that strength and vulnerability i.e. both sides that are part of 'being someone with a chronic illness or disability', are recognized. This does justice to their abilities and their occasionally limited capabilities.

By linking various theories to this story it becomes clear that not all people with a chronic illness or disability can be empowered and self-reliant throughout their lives. The image that depicts people with a chronic illness or disability as 'healthcare consumers' with control over their own lives may sometimes be true, but more often than not it is not the case.

Living with a chronic illness or disability may be associated with feelings of sadness and loss, but also with unmet basic needs, such as a sense of security. Once the chronic illness or disability has been accepted, feelings of grief and loss can return again in full force, triggered by an event or by deteriorating chronic illness or disability. These stages of grief and unmet needs can crop up, recursively, several times throughout the life course.

When living with a chronic illness or disability, it is not important whether someone is a 'mature healthcare consumer' or a 'dependent insecure patient'. But it is a fact that he or she regularly experiences both states, and needs to learn to cope, together with others in the vicinity, with both aspects simultaneously. A welcoming environment for participation of people with a chronic illness or disability would take account of both their strength and their vulnerability.

## **EXPLORING CRITERIA OF PEOPLE WITH A CHRONIC ILLNESS AND DISABILITY IN THE NETHERLANDS**

The representatives of people with a chronic illness or disability participate in projects on research and quality of care in the Netherlands. The problems they encounter while doing so are investigated in Chapter 3 about “Patients at the Negotiating Table. Exploring appraisal criteria of Health Research and Quality of Care used by Patient Advocacy Groups in the Netherlands”. This study is a preliminary exploration in support of the definition of the research described in this thesis.

It investigates the current practice of assessment and appraisal conducted by people with an illness or disability used in the evaluation of scientific research and quality of care. The results of this study enabled us to ascertain where the problems lie, and to clarify the research questions.

Three initial criteria in the areas of policy, research and quality of care, emerged from this initial exploratory study. These three criteria were found to be important to representatives of people with chronic illness or disability. These criteria were: *relevance*, *empowerment*, and *ethics & safety*. The demand for criteria and for practical instruments or methods to be used by representatives of people with a chronic disease or disability was loud and clear. These people need more support and something to hold on to during their involvement. This would have to be in the form of a tool or reference document. A need was also felt for more structured appraisal using a limited number of subjects important to their peer group. With these subjects and several pre-prepared questions they would be able to appraise a document more quickly and find arguments in a discussion more easily. Finally the study identified the need for training and support before and during appraisal activities.

## **INVENTORY OF ISSUES THAT MATTER FROM LITERATURE**

Chapter 4 is about “Patient issues in health research and quality of care: an inventory and data synthesis”. It describes an international literature study into the issues that matter to people with a chronic disease or disability in the domains health research and quality of health care. The results provide an inventory of these issues as far as they are known and acknowledged in the scientific literature. It soon became clear that there is very little about such issues in primary scientific sources. Publications from governments, international organisations and information provided by groups of people with a chronic disease or disability themselves, were needed in order to get a more complete picture. These publications are usually referred to as secondary and tertiary or ‘grey’ literature.

A total of 35 issues that matter to people with a chronic disease or disability were established. Some 13 of these issues were only found in tertiary or ‘grey’ literature. These 13 ‘missing’ issues (privacy, relevance, access, gender, pain, age, fear, consent,

communication, education, complaints, compensation and alternative methods) reveal a gap in the scientific literature, and mainly involve fundamental and personal values and quality of life issues (Table 1).

Table 1 Issues that matter to people with chronic illness or disability

| No. | Issue Description | Found only in grey Literature | No. | Issue Description | Found only in grey Literature |
|-----|-------------------|-------------------------------|-----|-------------------|-------------------------------|
| 1   | empowerment       |                               | 21  | access            | x                             |
| 2   | information       |                               | 22  | complaints        | x                             |
| 3   | safety            |                               | 23  | consent           | x                             |
| 4   | health system     |                               | 24  | social security   |                               |
| 5   | cost              |                               | 25  | buildings         |                               |
| 6   | lifestyle         |                               | 26  | communication     | x                             |
| 7   | choice            |                               | 27  | values            |                               |
| 8   | disability        |                               | 28  | education         | x                             |
| 9   | effectiveness     |                               | 29  | gender            | x                             |
| 10  | method            |                               | 30  | pain              | x                             |
| 11  | quality of life   |                               | 31  | self-care         |                               |
| 12  | diversity         |                               | 32  | age               | x                             |
| 13  | medical file      |                               | 33  | compensation      | x                             |
| 14  | quality           |                               | 34  | fear              | x                             |
| 15  | family, friends   |                               | 35  | alternatives      | x                             |
| 16  | privacy           | x                             |     |                   |                               |
| 17  | relevance         | x                             |     |                   |                               |
| 18  | cross border      |                               |     |                   |                               |
| 19  | dignity           |                               |     |                   |                               |
| 20  | ethics            |                               |     |                   |                               |

## STRUCTURED APPRAISAL AND EVALUATION IN PRACTICE

Chapter 5 is about “ Structuring patients advocates’ appraisal and evaluation of health research and quality of care”. The issues, values and criteria that are relevant to people with a chronic illness or disability in practice were further investigated in this chapter. In a series of focus groups, round table discussions and interviews, a draft set of criteria was debated, adjusted and prioritized by people with a chronic illness or disability. The initial aim of the research was to find values behind the issues that are important to these people in their daily life. This resulted in 4 different value group categories: fundamental, quality of life, quality of care, and empowerment / involvement.



The term ‘fundamental’ value in this thesis is used to identify those values that are of the utmost importance to people. These values relate to basic conditions to be able to function socially and psychologically. The participants in this study identify these fundamental values as being the most important. Only after these issues have been taken care of is a discussion about the aspects of quality of life possible. Only after the first two values have been secured, can the issues relating to the third and fourth value groups, i.e. quality of care and involvement respectively, be the subject of discussion and activities. For example, participants clearly state that feeling safe and respected is more important than good communication with a care professional or a say in the treatment process. This sequential order of importance can be depicted as an ‘involvement iceberg’ (Figure 1). Only the tip of the iceberg is above water level. This represents the people who are involved, take part in discussions, whose voices are heard, and who have secured the fundamental and quality of life value related issues in their life.



Figure 1 The involvement iceberg showing value-related issues



## **IMPLEMENTING ISSUES AND VALUES OF PEOPLE WITH A CHRONIC LUNG ILLNESS**

Chapter 6.1 about involvement of people with chronic lung illness, presents a seven-year case study that highlights the path to the current situation with people having a chronic lung illness being involved in the appraisal of scientific research proposals at Lung Foundation Netherlands (LFN). Implementation and practice of lung patient involvement practice in the LFN research cycle were described and analysed. This study investigated the basis for selection of research themes and which funding criteria were leading within LFN. The involvement of lung patients was then studied.

The scientific and societal relevance of research proposals are currently evaluated by all stakeholders. This was made possible by implementing an involvement method including a set of criteria from the point of view of people with lung disease. Implementing this involved training a group of people with lung disease and providing them with the developed appraisal and evaluating tool to evaluate the societal relevance from the patients' perspective. Scientific relevance and quality are evaluated and traded off separately in the research proposal approval or rejection process. This seven year case study provides an insight into the commitment of people with a chronic lung illness in the research cycle and into the pitfalls and complications that may arise.

Two related studies are included in this thesis since they elaborate on several points described in section 6.1. The study in section 6.2 describes the increasing level of involvement of people with chronic lung illnesses in LFN agenda setting since 2004. Although research priorities set by professionals and by patients are quite similar, the details tend to differ. People with a chronic lung illness give different priorities to specific subjects in lung research, for example aspects of fatigue, co-morbidity, and side-effects.

Shared responsibilities between people with Chronic Obstructive Pulmonary Disease (COPD) and health care professionals in practice are dealt with in section 6.3.

On one hand the dialogue between peer lung patients is very important. The safety of a group and sharing experiences among peers turns out to be an important means to give new meaning to the illness in the lives of people with COPD. On the other hand people with chronic illness or disability are expected to play an important role in their own recovery. This has consequences for the division of responsibilities among medical professionals and the people themselves. In-depth interviews with people with COPD, physiotherapists and a lung practitioner demonstrate that a shift in responsibilities requires a supporting attitude on the part of care providers and dialogue between patients and care professionals. People with COPD become co-owners of the recovery process. The notion that COPD is more than just a lack of air, and that mind and body mutually affect each other, is a first step towards investigating other problems in their life, and towards improving their quality of life. Exchanging ideas with respect for each other's views is important here.

## GENERAL DISCUSSION

The research questions are answered in Chapter 7 and recommendations are made for further research and for involvement practice.

The three main findings in this thesis' research are presented here.

The first main finding is the formulation of **issues and values** that matter to people with a chronic illness or disability. They constitute part of their experiential knowledge. The research resulted in 35 issues (see Table 1) that are important to these people in their life with illness or disability since they affect their functioning on societal and mental levels and their ability to join in with involvement activities. With the help of the values it was possible to divide the issues up into four different sequential groups: fundamental human values, quality of life, quality of care, and involvement.

The second main finding is the **set of appraisal and evaluation criteria** coming from and to be used by representatives of people with a chronic illness or disability during the evaluation of health research and quality of care. This set of six criteria, derived from the 35 issues, includes all the issues that matter to people with a chronic illness or disability. This set of criteria can be used during involvement activities, e.g. on appraisal of research proposals and on guideline development.

The set of criteria is about the relevance of quality of care or health research activities as seen from the perspective of these people. The criteria are also about whether the diagnostic or treatment activity improves their quality of life.

Further criteria involve ethics and safety aspects and quality of health care and health research activities. Furthermore the criteria are about information that can be well understood, e.g. using lay language, and about careful communication, e.g. the feedback of results to the group of people with the illness or disability concerned, and their organisation. Currently 1 set of criteria is being used for appraisal of research proposals and evaluation of e.g. health standards or guidelines. Comments from the field indicate separate sets of criteria might be useful for the research and care domains. Specific terms and context might be used. Further development of these is being planned for in 2014.

Finally the criteria are about involvement itself and the question as to whether a project or research are also based on ideas and needs expressed by people with a chronic illness or disability. The criterion about 'involvement' includes the issue 'right of say' which identifies it more as a process criterion than a content criterion. This criterion also addresses the point of these people being an equal partner in the project or activity and whether they are not only allowed to have a voice but may also be truly involved in making decisions.

The third and final main finding is about the **relationship between professionals and the involved people** with a chronic illness or disability. This relationship can facilitate a kind of

partnership which prevents parties from opposing one another. This kind of partnership requires commitment and support by all participants about the usefulness and added value of including the perspective of people with illness or disability. Linking the different perspectives of these people and the perspectives of professionals leads to a qualitatively better outcome that enhances current practice. This leads to research and guidelines that are both scientifically sound and scientifically and societally relevant in the eyes of people with a chronic illness or disability.

## RECOMMENDATION FOR FURTHER RESEARCH

**Changing balance:** the first recommendation is the question as to whether the presence of advocates of people with a chronic illness or disability and their voice actually disturbs the existing power balance, and if so, to what extent. What happens when people do not adjust to the dominant discourse in health care or research and introduce their own counter-story, as did the author of this thesis? What happens when their views are fundamentally different from those of other participants? Are they placing themselves outside the group or the debate altogether, or can this counter-story have some influence? Or is the balance of power between people with a chronic illness and professionals slowly shifting towards more equal roles in the debate? Are they, in other words, moving towards true partnership? It would be interesting to investigate these questions since they could shed light on how the voice of people with a chronic illness or disability could be more empowered within existing power relations and processes.

**Vulnerable people:** further research is also recommended into the question of how the experiential knowledge of vulnerable people who are not heard or who do not voice or express their views, can be used and utilized in their own interest for the appraisal of research and care activities. How can their experiential knowledge be included and seriously considered in health debate or decision making ?

**Stories as an instrument to gain insight:** it is finally recommended that alternative ways for people with a chronic illness or disability be further investigated with a view to understanding their situation and their life with its constraints and limitations. In Chapter 2 the author (Truus) wrote her story following the path between several critical moments in her life surrounded by illness and disability. She developed her story and reflected on it together with two others. This increased her insight into, understanding of, grip on and perspective in her life. Research could clarify whether this approach, or other modes of creative expression such as poetry or other artistic representations, also have a positive effect on other people with a chronic illness or disability.

## RECOMMENDATIONS FOR PRACTICE

**Monitoring:** listening to people with an illness or disability should be permanent practice in health care on all levels. This is what the WHO states in its health policy on citizens' rights and patient involvement (Health 21) for the European region. Ethics and human rights are mentioned in several generally accepted documents but they are not legally binding and are therefore not compulsory. There is therefore no guarantee that they are applied. It is recommended that organisations of people with a chronic illness or disability monitor this closely.

**Value structure:** values are a main driver behind human behaviour. Issues that matter to people with a chronic illness or disability are closely linked to values. A recommendation is to further implement the value structured criteria (iceberg), resulting from the research in this thesis, in practice.

**Counter-stories:** the dominant concept of resilient, sturdy and empowered people with a chronic illness or disability is under debate. These people are not mere health consumers with control over their own illness or disability. Other views, described in alternative or 'counter-stories' need to be taken up and considered in the health debate.

**Pictograms and symbols:** people with a mental disability or illness, e.g. Alzheimer's, but also illiterate people, require a special version of the criteria developed in this thesis' research. The choice of words, illustrations and pictograms needs to be adapted to their needs. Some people recognize a pictogram much more easily than they can read a text. Pictograms are also interpreted more accurately than words. The 'criteria fan' is a living document. Extending the criteria with other specific subjects and problems related to the daily lives of specific groups of people is both desirable and possible.

**Partnership:** people with a chronic illness or disability are still regarded as a threat to existing power relations in a project or a committee. Accordingly, their relatively new voice at the negotiation table is not seen as a positive development but as a formality that needs to be accepted but which is, in fact, not taken seriously. A clearly undesirable kind of involvement is apparent when people are invited merely for their formal presence, which is referred to as 'pseudo-involvement'. It is recommended that people with a chronic illness or disability only agree to be involved if it is on an equal footing with others occupied with discussion and decision making in a project, committee or debate.

**Capacity building:** people with a chronic illness or disability often find it difficult to ensure continuous involvement due to absence because of illness. A practical solution to this would be to be involved and work in duo-teams. This requires the availability of a sufficiently large number of people with a chronic illness or disability active in involvement on a regular basis. This calls for these people to be trained and educated in involvement activities, in relevant developments, and they need to know the facts about their peer

group. The larger the group of capable people available, the fewer problems with absence and interruption of the health dialogue and decision-making processes.

It is recommended that extra effort be put into reinforcing and supporting people with a chronic illness or disability who represent their peer group and who are involved in discussions and decision making. All stakeholders, both vulnerable and strong, must be given an opportunity to table their issues, to be heard and to be taken seriously.

**CRITERIA FAN****1 RELEVANCE**

- 1.1 Does this improve the health of the people with illness or disability ?
- 1.2 Is their diversity being taken into account ?
- 1.3 Is this based on their questions and needs ?
- 1.4 Can the project results be used in practice ?

**3 QUALITY OF CARE**

- 3.1 Does this improve health care for the people with illness or disability ?
- 3.2 Is their diversity being taken into account ?
- 3.3 Are their social network and environment being taken into account ?

**5 INFORMATION AND COMMUNICATION**

- 5.1 Can the information be properly understood by the people with illness or disability ?
- 5.2 Are these people and their organisations being informed about project results ?
- 5.3 Is the information provided correct and complete, also on possible complications ?
- 5.4 Are these people having the possibility to explicitly agree or refuse (informed consent) ?

**2 QUALITY OF LIFE**

- 2.1 Does this improve the health related quality of life of the people with illness or disability ?
- 2.2 Is their societal participation being improved ?
- 2.3 Are their fundamental values being respected and being used as guiding principle ?
- 2.4 Are the project results beneficial to them in practice ?

**4 ETHICS AND SAFETY**

- 4.1 Are the means (e.g. pain, absence of work or school) justified by the goals (e.g. better medication) ?
- 4.2 Is the safety of participants, patients and test persons being ensured ?
- 4.3 Are people concerned having explicit freedom of choice ?
- 4.4 Are their social norms, values and dignity being respected ?
- 4.5 Are the health professionals respecting rules, codes of practice and guidance ?

**6 INVOLVEMENT (precondition)**

- 6.1 Are the interests of people with illness or disability taken into account ?
- 6.2 Are they being included as equal discussion partners ?
- 6.3 Are they being regarded as full citizens ?
- 6.4 Is their experience included as a source of experiential knowledge in project, guidance or research ?
- 6.5 Are they being supported in their involvement effort ?