The role of the client in patient safety

*a necessity, not a desirability*

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**Research carried out for:**
This report has been prepared on behalf of the Netherlands Organisation for Health Research and Development (ZonMw). The views in this report are those of the researchers and not necessarily of ZonMw.

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Appendix 1 Web search: intervention overview (method of participation and level and intervention content)
Appendix 2 Web search: intervention overview (initiators and intervention content)
Appendix 3 Topic list interviews
The Ministry of Health, Welfare & Sport has set up a national patient safety programme in the Netherlands, implemented by ZonMw, which comes to an end in 2009. The question now is which themes lend themselves to a follow-up patient safety programme. ZonMw has asked the Dutch Institute for Healthcare Improvement CBO (CBO), in view of its expertise in the area of patient safety and patient participation, to conduct a preliminary study into the role of the client in patient safety in this context.

The purpose of this preliminary study is to report existing knowledge and gaps and to make a recommendation to ZonMw about the elaboration of the theme ‘the role of the client’ in the future patient safety programme. It is a matter of recommendations for the potential and desired role of clients based on current insights, necessary further research into this theme and desired further developments in practice. Knowledge and opinions have been collected from the science, theory and practice by means of a literature review, a web search and an interview session with national experts. Finally, the findings have been presented to experts, leading to the conclusions and recommendations.

The preliminary study shows that the client has a unique perspective on the care process, which is a valuable addition to the knowledge of the professional. Care provision is less than optimal without a contribution by the client, because the client is the only one to experience the entire care process.

The way in which the client can fulfil a role is still unclear at the moment; it depends on the degree to which clients are willing and able to participate and the skills they need to do so. Not all clients are able or willing to take a role in patient safety. A role of a client is therefore always voluntary and may serve as an additional verification moment in the care process. In his role in patient safety the client can act as adviser or controller of his treatment process, but the professional retains final responsibility for the patient safety of the client.

The attitude and skills of the professional are also crucial factors in giving further substance to the role of the client. The creation of an open culture in which the perspective of the client is involved is essential and starts with the relationship of the professional and the client. The client needs the right information and equipment to know what patient safety means, what risks there are and what he can contribute to the care process to enhance his own safety.

The unique perspective of the client must also be involved in the drafting of guidelines, protocols, care standards and patient safety policy. This also contributes to the development of a transparent and reliable care system that is clear and understandable to clients and professionals.

Existing (inter)national interventions are mainly aimed at information and tips for the client and his family or representative, a common example of which is the patient safety card. Few interventions have yet been developed that support the professional with involving the client in patient safety. In the further development of interventions it is important that the professional’s perspective is involved in addition to the client’s perspective. If the interventions aimed at professionals link up with existing legislation and regulations, motivation for their use is greater. International research into the effect of interventions with regard to the role of the client in patient safety remains limited. For a positive impact of interventions it is important that interventions are aimed at the relationship (and the dialogue) between professional and client.

The Netherlands is leading the way when it comes to client collectives (client councils and client representatives). However, the role of client councils in healthcare facilities and the role of client collectives are currently underutilised. The professionalisation and facilitation of client collectives makes it possible to involve the perspective of the client in the (annual) safety policy of healthcare facilities and redesign of care processes. At the same time the discussion of incidents, the development of the reception of (former) victims and the
organisation of aftercare for (former) victims is very important for the creation of an open culture.

The gaps in the development of a role of the client in patient safety are visible in:

a) the present organisation of care (insufficiently transparent and reliable),

b) the lack of insight into the values, knowledge, attitudes, needs, ideas and readiness of clients to play a role in patient safety and

c) insufficient attention to the skills of professionals and clients.

The motivation of professionals is the guiding principle for the support and encouragement of clients to play a role in patient safety.

The essence for the development of the role of the client in patient safety is the relationship between the professional and the client. Both the professional and the client first need awareness of the fact that a role of the client is possible. They also need motivation and skills to enable the client to play a role. In this way the self-efficacy (confidence in their own ability) of professionals and clients actually to enable the client to fulfil a role in patient safety grows. A number of themes have an impact on the relationship between the professional and the client and are important for further development in an integrated approach:

- professionalising and facilitating client collectives (client councils and client representatives) so that they can fulfil a role in care policy and primary (redesign of the) care process;
- research is needed into the impact and the importance of and the interaction between the five context factors on which the fulfilment of the role of the client depends:
  o the specific client (knowledge and opinions),
  o the illness (phase and characteristics),
  o the professional (knowledge, opinions and inviting behaviour),
  o the setting and
  o the type of safety behaviour that the client exhibits;
- researching existing initiatives (interventions) for their impact and developing or continuing to develop them, innovating and extending them to other settings;
- developing a national information and knowledge centre for all parties in healthcare with public information, tools and education to give substance to the role of the client in patient safety;
- setting up a training programme (for example, a patient safety officer programme) for healthcare organisations, aimed at leadership, culture and structure;
- evaluating and optimising the legislation and regulations relating to the role of the client;
- involving the insight of the client in guidelines, indicators and care standards and making the healthcare options clear and understandable to the client.

This integrated approach makes a sustainable implementation of the role of the client in patient safety possible.
Chapter 1  Introduction

This chapter contains the introduction (1.1) and the statement of the problem (1.2).

1.1 Introduction

The theme of patient safety is a socially topical theme that is high on the agenda of the government, patient representatives, healthcare providers, professionals, regulators and healthcare insurers. Patient safety can be described as: “the (almost complete) absence of (the chance of) harm (physical and/or mental) inflicted on the patient as a result of the failure of care providers to act according to professional standards and/or failings of the healthcare system. The basic principle is the pursuit of safe system design, so that errors are prevented or no longer lead to (irreparable) harm (NIVEL 2007)”. Safe care is certainly not synonymous with risk-free care, but it does mean that the consequences of human, technical and organisational imperfections in the care system are nullified as far as possible.

There are now initiatives to reduce unintended harm to clients in all sectors of healthcare. In addition, the strengthening of the role of the client and patient organisations is high on the social and political agenda. Value is increasingly being attached to the involvement of clients in the organisation and improvement of care. Patient organisations are acquiring an ever more prominent role in consultation and decision-making. In society, and therefore in healthcare too, a development can be seen in which the client is becoming increasingly empowered and to an increasing degree is taking control. The involvement of clients in an area such as patient safety therefore provides a unique opportunity to improve patient safety from a new perspective.

The contribution that clients have so far made to making care safer is limited. Their role remains neglected and has not received systematic attention. This is in part because of the assumption that the primary responsibility for safety lies with the care providers. This also explains why the input of healthcare professionals themselves and the management of healthcare facilities is required in most improvement initiatives.

There is knowledge available and there are examples of interventions in practice in which clients play a role in improving the safety of their own care process both internationally and nationally, but there has so far been no review of existing literature, knowledge and practical examples in this field. Further research into this subject is still at an early stage, which means that there is still little insight into the effects, the potential risks and limitations and the desirability of giving clients a role in patient safety.

This report considers the creation of a knowledge review from an exploratory qualitative survey of the role of the client in patient safety. The survey focuses on both national and international knowledge in all sectors of healthcare and has collected knowledge and opinions from science, theory and practice by means of a literature review, a web search and an interview session with national experts. Finally, the findings from the investigation and the gaps found were presented to experts and the recommendations follow.

1.2 Statement of the problem

The Ministry of Health, Welfare & Sport has set up a national patient safety programme in the Netherlands, implemented by ZonMw, which comes to an end in 2009. The question now is which themes within patient safety are suitable for a follow-up patient safety programme. ZonMw is implementing the programme and has asked the Dutch Institute for Healthcare Improvement CBO (CBO), in view of its expertise in the area of patient safety and patient participation, to conduct a preliminary study into the role of the client in patient safety in this context. The purpose of this preliminary study is to generate and report existing knowledge and gaps in a knowledge review with a view to making recommendations to ZonMw about
the elaboration of the theme ‘the role of the client’ in the future patient safety programme. It is a matter of recommendations for the potential and desired role of clients based on current insights, necessary further research into this theme and desired further developments in practice. The statement of the problem that follows from this is: what knowledge is there of the role of the client in the improvement of patient safety?

The ZonMw Patient Safety Study makes a suggestion for a working definition for the participation of clients in patient safety (May 2008): ‘the utilisation of unique hands-on expertise of clients with a view to enhancing the safety of the care’. This definition is aimed at healthcare providers ‘learning to use’ the hands-on expertise. A definition in which the client himself acquires a more active role is: “the actions that patients take to reduce the likelihood of medical errors and/or the actions that patients take to mitigate the effects of medical errors when they occur (Davis et al. 2007)”’. This is a matter of the empowerment/strengthening of the client to make a contribution to patient safety. In this preliminary study a combination of the two said definitions is used as the basic principle: the teaching of skills to professionals and the strengthening of the role of the client. The statement of the problem will be answered on the basis of the following sub-questions:

1. What knowledge is there of the insight into the role of clients in patient safety with regard to the effects, risks and influencing factors?
2. What knowledge is there of the possible interventions of individual patients and patient collectives with regard to the role of the client in patient safety?
3. Of which of the said interventions is the effect not known, but have priority for further study?
4. What knowledge is there of the views of patients and care professionals about the role of the client in patient safety?
5. What gaps are there in the present development of a responsible role of the client in patient safety in respect of insight into the role of the client, possible interventions and views of patients and professionals?

The chapters that follow set out the organisational framework (chapter 2), the method (chapter 3) and the results of the literature review, the web search, the interviews with experts and the expert meeting (chapter 4) in turn. Finally, recommendations for the elaboration of the theme ‘the role of the client’ in the follow-up patient safety programme are made to ZonMw on the basis of the conclusions (chapter 5).
Chapter 2  Organisational framework

The organisational framework described below is used in the preliminary study for a systematic survey of the existing knowledge of the possibilities of client participation, effects, limitations and desirability. The steps of the participation ladder are used for the way in which the client participates (Binkhorst et al., 2006), the participation ladder providing insight into the degree of participation of the client and the role for the client (patient) that follows from it.

<table>
<thead>
<tr>
<th>Step</th>
<th>Client Role</th>
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<tbody>
<tr>
<td>Information</td>
<td>the patient is aware</td>
</tr>
<tr>
<td>Consultation</td>
<td>the patient contributes to discussion and thinking</td>
</tr>
<tr>
<td>Advice</td>
<td>the patient advises</td>
</tr>
<tr>
<td>Partnership</td>
<td>the patient co-decides</td>
</tr>
<tr>
<td>The patient has control</td>
<td>the patient decides</td>
</tr>
</tbody>
</table>

A three-way split is used for the level at which the client participates, the first level of which is the micro level, which means the individual client in his own treatment process. This is about the way in which clients have the opportunity to exert influence on the safe course of their own care process. The following aspects come up for discussion here:

1. Making a well-informed choice of provider.
2. Contributing to the determination of the right diagnosis.
3. Participating in the decision-making about treatments and procedures.
4. Contributing to safe use of medication.
5. Participating in infection control mechanisms.
6. Checking that the files have been completed accurately.
7. Observing and checking the care process.
8. Recording and reporting complications and incidents.
10. Developing the design and the improvements of the service.

It is possible that the inventory will bring other aspects to light in addition to the above.

For the second level, the meso level, the client is seen as a representative at strategic level in a healthcare facility or practice, for example in client councils.

Finally, the participation of the client at macro level is seen at national level through client associations, client panels, umbrella organisations, etc. From the context in which the participation must take place five categories can be distinguished that influence client participation in safety:

1. Client-related (for example demographic characteristics).
2. Illness-related (for example the seriousness of the illness).
3. Related to the care professional (for example knowledge of and belief in participation).
4. Related to the environment in which the care takes place (primary, secondary or tertiary).
5. Task-related (for example, whether the professional possesses the skills to challenge the client to the desired role).

Finally, on the basis of the desirability or need of client participation in safety, the following aspects are discussed:

1. Knowledge of the effects of client participation in the improvement of patient safety.
2. Knowledge of the desirability of client participation on the basis of clients and professionals.
3. Knowledge of the risks and/or dangers of client participation?
Chapter 3  Method

A qualitative research method was chosen for the performance of the preliminary study, with quantitative additions where possible. The following four steps in the preliminary study into the role of the client in patient safety lead to the collection of existing knowledge of the role of the client in patient safety.

1. The literature review involves looking for relevant articles and publications, as is also done in the development of guidelines.
2. In the course of the literature review a web search is also carried out. Here the focus is on finding concrete interventions and their effects and on views of patient participation in patient safety.
3. The third part of the collection of information consists of interviews with Dutch experts in the field. These interviews also look at knowledge of existing forms of patient participation, effects, influencing factors, risks and the desirability of the role of the client.
4. Finally, the results found are submitted to experts in the field for review in order to produce recommendations for the follow-up patient safety programme.

The sections below describe how the literature review (3.1), web search (3.2), the interviews with experts (3.3) and the expert meeting (3.4) took place. Finally, the limitations of the collected results follow (3.5).

3.1 Literature review

The literature review was as far as possible based on evidence from published scientific research. Relevant articles were sought by carrying out systematic search actions as used in guideline research. The search took place between 1999 and 2009 in the Medline, Embase, Psycinfo and CINAHL databases. Approximately 20 different key words were used in the databases and English and Dutch-language articles were selected. The main key words used were:

“quality health care, patient safety, patient involvement, patient participation, patient empowerment, patient refuse, patient role, engaging patient, client (other sectors), safety interventions, errors, risks, (patient as) partner, partnership, (learning from) patient experience, patient perspective, service user perspective, consumer perspective, involvement tools + safety, participation tools + safety, safety decision making”.

The search queries were divided into a number of elements according to the PICO method:

<table>
<thead>
<tr>
<th>P</th>
<th>Patient population</th>
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<tbody>
<tr>
<td>I</td>
<td>Intervention</td>
</tr>
<tr>
<td>C</td>
<td>Comparison/control</td>
</tr>
<tr>
<td>O</td>
<td>Outcome</td>
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Some 541 articles emerged from the literature review, including a number the same. From this list of articles three CBO consultants decided which literature was relevant for the preliminary study from the summaries of the articles, selecting 38 articles relating to the research questions. This literature was analysed by classifying the outcomes in a research matrix, which was set up on the basis of the research questions and served as a basis for the description of the results in chapter 4.
3.2 Web search

A web search took place to make an inventory of concrete interventions. The search was for any effects thereof and the standpoints and opinions on patient participation in patient safety. Search terms were drawn up in Dutch and English prior to the web search. The main key words used were:

“patient safety, patient involvement, patient participation, patient role, patiëntveiligheid, rol patiënt, rol cliënt, patiënten betrekken”

[“…] patient safety, role of patient, role of client, involving patients”]

These search terms were entered into an online search engine and all the relevant hits were viewed. If the ‘hit’ referred to a web site, the web site concerned was examined in detail for any other concrete interventions. All the hits were incorporated in a table. The information was subdivided into four categories:

- concrete client/patient participation interventions,
- scientific articles,
- practice-oriented articles or documents, for example in specialist journals,
- names of relevant persons in the patient safety and patient participation field.

All the concrete interventions found were incorporated into the results analysis. The scientific articles were compared with the articles that emerged from the literature review and were included in the literature analysis. The practice-oriented articles were all assessed for usability and, if relevant, included in the analysis. From this two Dutch-language articles emerged that have been published in manuals. These articles were included in the analysis together with the other literature sources. The results section of the web search does therefore only include the information on concrete interventions. The relevant persons who emerged in the web search were included in the interview session.

The results were incorporated into a matrix based on the elements from the theoretical framework and concern the method of participation, the target group, the level of participation and the intervention content (patient safety aspects) (chapter 4).

3.3 Interviews with experts

The respondents interviewed were from healthcare organisations with a direct and indirect involvement in cure, care, primary care, patient organisations and (inter)national policy and research in relation to patient safety. The table below shows who from which organisation was prepared to act as a respondent. The respondents were asked which organisations and persons in their view were also of interest for an approach for an interview for the purposes of this subject and/or what literature and/or knowledge they had on this subject.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Respondent</th>
<th>Position</th>
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<tbody>
<tr>
<td>Dutch Institute for Healthcare Improvement CBO</td>
<td>Mrs T. Binkhorst</td>
<td>Team manager &amp; senior consultant</td>
</tr>
<tr>
<td>Dutch Council for the Chronically Sick and Disabled</td>
<td>Mrs H. Cliteur</td>
<td>Director of Policy</td>
</tr>
<tr>
<td></td>
<td>Mrs P. Calkoen</td>
<td>Policy adviser</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medication policy</td>
</tr>
<tr>
<td>Consumers’ Association</td>
<td>Mr C. Jakobs</td>
<td>Policy adviser</td>
</tr>
<tr>
<td>Consumer</td>
<td>Mr J. Janssen</td>
<td>Client</td>
</tr>
<tr>
<td>St. Dimitri</td>
<td>Mr J. Kleijn</td>
<td>Founder</td>
</tr>
<tr>
<td></td>
<td>Mr J. Midavaine</td>
<td>Member</td>
</tr>
<tr>
<td>Isala Klinieken</td>
<td>Mr H. Molendijk</td>
<td>Centre medical manager &amp; initiator</td>
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The role of the client in patient safety
a necessity, not a desirability

<table>
<thead>
<tr>
<th>Patient Safety Centre</th>
<th>Paediatrician/neonatologist</th>
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<tbody>
<tr>
<td>National Organised Primary Care Association (LVG)</td>
<td>Mrs A. Venema  Deputy director</td>
</tr>
<tr>
<td>National Co-determination Centre (LSR)</td>
<td>Mrs D. Korporaal  Senior policy adviser &amp; project coordinator</td>
</tr>
<tr>
<td>LEVV</td>
<td>Mr G. Hunink  Consultant</td>
</tr>
<tr>
<td>St. Maartenskliniek</td>
<td>Mr Kocken  RD&amp;E Quality Coordinator</td>
</tr>
<tr>
<td>Medinrisk</td>
<td>Mrs A. Hamersma  Policy adviser</td>
</tr>
<tr>
<td>Nervermedis</td>
<td>Mr M. de Leeuw  Chair</td>
</tr>
<tr>
<td>NPCF</td>
<td>Mrs S. Ouboter  Policy adviser</td>
</tr>
<tr>
<td>Dutch Hospitals’ Association (NVZ)</td>
<td>Mrs L. Werther-Voorrecht  Quality and Work policy adviser</td>
</tr>
<tr>
<td>Order of Medical Specialists (OMS)</td>
<td>Mrs M. Kallewaard  Scientific council &amp; quality secretary</td>
</tr>
<tr>
<td>Netherlands Iatrogenic Negligence Foundation</td>
<td>Mrs S. Hankes  Chair</td>
</tr>
<tr>
<td>TNO Quality of Life</td>
<td>Mr T. Rövekamp  Senior researcher Care Innovation Department</td>
</tr>
<tr>
<td></td>
<td>Mr R. Bezemer  Senior researcher Care Innovation Department</td>
</tr>
<tr>
<td>UMCU Patient Safety Knowledge Centre</td>
<td>Mr I. Leistikow  doctor/member of Board of Management Knowledge centre coordinator</td>
</tr>
<tr>
<td>Care SMS</td>
<td>Mrs B. Heemskerk  Care SMS programme manager</td>
</tr>
<tr>
<td>Zorgbelang Nederland patient organisation</td>
<td>Mr P. Kuhlmann  Policy adviser</td>
</tr>
<tr>
<td>Zorgbelang Overijssel patient organisation</td>
<td>Mrs L. Kievit  Cure policy adviser</td>
</tr>
</tbody>
</table>

The 21 interviews with 24 respondents were largely conducted by telephone, three interviews taking place face-to-face on site and one interview taking place by email. The interviews were conducted by four CBO consultants with reference to a topic list sent to most of the respondents in advance. The semi-structured nature of the interviews made it possible to reveal as much information about the subject as possible. The interviews were summarised in writing by the interviewer on the basis of the notes from the interview. At the request of the respondents the results from the interviews were reproduced anonymously. The results of the interviews were incorporated into a matrix corresponding to the matrix drawn up for the literature on the basis of the research questions. The results are described in chapter 4 on the basis of this classification.
3.4 Expert meeting

Once the results of the literature review, the web search and the interview session had been collected, they were presented for review to experts in the field at an expert meeting. Experts from the different healthcare sectors were invited to the meeting, although not everyone was able to take part because of the summer period. If parties were unable to take part, a telephone interview was chosen. In this way everyone was involved in the preliminary study.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Expert</th>
<th>Position</th>
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<tbody>
<tr>
<td>Dutch Institute for Healthcare Improvement CBO</td>
<td>Mrs S. Lobensteijn</td>
<td>Consultant</td>
</tr>
<tr>
<td>St. Dimitri</td>
<td>Mr J. Midavaine</td>
<td>Member</td>
</tr>
<tr>
<td>Mr J. Kleijn</td>
<td></td>
<td>Founder</td>
</tr>
<tr>
<td>NPCF</td>
<td>Mrs S. Ouboter</td>
<td>Policy adviser</td>
</tr>
<tr>
<td>NVZ/SMS (cancelled)</td>
<td>Mrs M. Kroeze</td>
<td>SMS Care programme leader</td>
</tr>
<tr>
<td>Trimbos Institute (absent)</td>
<td>Mrs I. Kok</td>
<td>Management &amp; Policy Programme</td>
</tr>
<tr>
<td>UMC Utrecht Patient Safety Knowledge Centre</td>
<td>Mrs Y. van der Tuijn</td>
<td>Paediatric IC nurse &amp; Nurse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Practitioner</td>
</tr>
<tr>
<td>Ministry of Health, Welfare &amp; Sport</td>
<td>Mrs M. Prins</td>
<td>Curative Care Management</td>
</tr>
<tr>
<td>Mr G. Buijs</td>
<td></td>
<td>Market and Consumer Management</td>
</tr>
<tr>
<td>V&amp;VN</td>
<td>Mrs F. Bolle</td>
<td>Senior policy adviser V&amp;VN</td>
</tr>
<tr>
<td>ZonMw</td>
<td>Mrs H. Bonink</td>
<td>Programme coordinator</td>
</tr>
</tbody>
</table>

3.5 Limitations

The literature review involved searching for English and Dutch search terms, as a result of which the literature from non-English-language countries has perhaps been neglected. Nevertheless, the developments, research results and opinions from other countries did emerge in English-language articles in the literature review. Consequently, a large part of the existing literature has probably been surveyed.

As far as the web search is concerned it must be noted that this method has the drawback that not all the existing interventions in practice come to light. It may be that there are examples in practice that are not available on the internet. It could be that predominantly certain types of intervention are put on the internet, for example, only the interventions in which information is given to patients and professionals. To deal with this we also looked for interventions in the literature review and the interview session. In addition, the internet is very much in development and there may be new initiatives online now that the search has been done.

The interviews were held with experts from a variety of disciplines. They were confined to key figures, which means that (other) perspectives of persons from the same discipline were neglected. For this reason the experts chosen were those who spoke on behalf of their grassroots and during the interviews they were asked whether they knew perspectives of others on this subject. The interviews were conducted by four different consultants, so there may have been differences in the method of asking questions and the summarising of the interview. The interviews were analysed by one interviewer and the results of this were presented to the other interviewers. The detailed interviews were not presented to the interviewees because of the time scale of the preliminary study. The outcomes of the literature review, the web search and the interview session were submitted to an expert panel for review to increase the validity of the research.
Chapter 4 Results

This chapter describes the results of the literature review, the web search, the interview session and the expert meeting.

4.1 Literature review

In the literature review we searched for what is known of the role of the client in patient safety. The following sub-questions provided guidance in this regard:

1. What is the knowledge of the role of the client with regard to experiences and effects?
2. What is the knowledge of the role of the client with regard to limitations, risks and influencing factors?
3. What is the knowledge of interventions for individual clients with regard to patient safety?
4. What is the knowledge of client collectives with regard to patient safety?
5. What is the knowledge of research into and evaluation of the effect of the said interventions?
6. What is the knowledge of wishes and views of clients, professionals and policymakers regarding the role of the client in patient safety?
7. What gaps are there for the development of a responsible role of the client in patient safety?

In the sections below the results of the literature review are summarised in the form of a critical consideration. The references of the articles can be found in the bibliography and the matrix in which the literature has been analysed can be obtained from the CBO.

4.1.1 Knowledge of the role of the client with regard to experiences and effects

What experiences are there in practice if the client acquires a role in patient safety and what effects are observed in that same practice? Patient safety cannot be tackled effectively if the client perspective is not fully in view. An active role of the client must be encouraged and recognised in:

- the making of an accurate diagnosis,
- the decision for the right treatment,
- the selection of an experienced and safe provider,
- the recording and monitoring of treatment.

Strategies can be developed with the input and participation of trained clients and family that contribute to patient safety. In the redesign of critical care processes or organisational processes the input of clients and family may be essential for the creation of patient safety. Their insight into their own care process is unique.

Standards such as patient safety guidelines and protocols are usually drawn up from the perspective of the organisation and the professional (for example, for high-risk medication). These standards motivate the professional insufficiently actually to follow them. If the perspective of the client and his family or representative is involved in the drafting and implementation, the standards are applied more consistently.

The involvement of clients in patient safety only succeeds if the professional is motivated. If professionals have acquired experience of involvement of clients and family, this increases their confidence in the effectiveness of that role and they will encourage the involvement of clients themselves.
On the basis of research and practical examples there are effective recommendations for the way in which the client can play a role in patient safety. To put the recommendations into practice however clients must have a sense of self-efficacy (confidence in their own ability). A greater sense of self-efficacy leads to greater readiness on the part of clients actually to follow the recommendations. Clients also find it easier to ‘reward’ good behaviour of professionals than to address professionals about failings. A practical study of the willingness of clients to be involved in the improvement of hand hygiene of professionals reveals that the majority of clients think that the client must be involved. Only in a few cases do clients ask the professional whether he has washed his hands, in spite of the fact that they see that the professional is not washing his hands. The client finds it easier to give a positive judgment by having a display light up: ‘thank you for washing your hands’. The thought that a professional knows that clients pay attention to hand washing has a positive effect, even if only an occasional client addresses the professional or uses the display. Clients are also very motivated to observe whether their care is correct. This is more difficult for acute, seriously ill clients and clients with complex care needs.

Clients are less aware of risks in healthcare than of risks in traffic. They do not (yet) realise that, just as they do in traffic safety, they can have a role in their own patient safety. The question is whether clients are indeed willing and able to report safety-related aspects in care and the risks with it. Clients may not always be aware what does or can go wrong, do not interpret a situation correctly, do not have the right resources or have qualms about it. There is material available that advises clients on what they can do themselves to prevent errors and harm, but:

- the client perspective is often neglected in the development of material,
- clients receive little practical support in putting recommendations into practice,
- the reaction of professionals is not always encouraging for clients,
- in some materials an (incorrect) shift of the responsibility from the professional to the client is assumed,
- advice for clients to put behaviour of professionals to the test may be difficult for clients.

When clients and family are involved in analysing incidents, they understand better how the care has been organised. Stories of clients also prove to be powerful in this in bringing about awareness and behavioural change of professionals.

4.1.2 Knowledge of the role of the client with regard to limitations, risks and influencing factors

For clients the following limitations on taking an active role emerge:

- vulnerability of clients (physical/mental/dependence),
- poor communication,
- emotional distance between client and professional/care organisation,
- sense of hierarchy,
- resistance of professionals,
- cultural differences between professionals,
- overconcern of the organisation.

A potential danger is the shifting of the responsibility for patient safety from the professional to the client, with the consequence that clients acquire a responsibility they cannot bear. It is unknown to what degree clients are willing and able to be involved in safety and there is a lack of research into models of patient participation in patient safety. Another risk is that the client does not feel that he is allowed or able to comment, because the professional knows what he is doing and always acts correctly. Clients are also inclined to give professionals
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Protection and the inclination above all to report actual harm is greater than bringing possible harm to someone’s attention.

There is a lack of a clear definition of patient participation and the criteria with which clients must comply to acquire a role in their illness and care. What knowledge and skills do they need? Their opinion alone is not enough to be an expert. Apart from knowledge clients lack alertness. This is a matter of specific information about where and when errors can occur. Public information about this may contribute to the self-efficacy and involvement of the client as a partner in care provision, but this only works if clients have the confidence that their involvement really has an effect and if they have confidence in their own ability to play a role in patient safety. It should be noted that the client is least quick to dare to ask questions that have direct involvement with professional autonomy.

What influencing factors does the literature report if the client acquires a role in patient safety and what effects of it are observed in practice? The client is the only one who goes through and experiences the entire process and may therefore be a specific, complementary and consequently indispensable source of information, indispensable that is in the implementation of ‘evidence-based medicine’. Chronic clients in particular are seen as hands-on experts. The client is not however always aware of the risks associated with a hospital stay, for example. People have the impression that a hospital is reasonably safe, but clients do point out that errors are made and that some clients suffer unnecessary harm because of incorrect treatment. A collective approach by clients, family members, professionals and care organisations is needed to reduce the risks of error and to increase the reliability of the healthcare.

4.1.3 Knowledge of interventions for individual clients with regard to patient safety

General initiatives aimed at interventions of individual clients with regard to a role in patient safety are:

- Clients have (paid) involvement with the education of professionals, but also with care innovations and the decision-making in this regard. The client perspective is incorporated at every level of the organisation into the development of organisational policy and the setting of priorities therein.
- Clients themselves record ‘adverse events’ in their care, which are often not found in the hospital’s reporting system. A hypothesis is that clients are evidently capable of recording different ‘adverse events’ from professionals.
- Clients and family are involved in safety rounds on wards. The question about which they are concerned or where they see dangers takes centre stage, which leads to an open discussion about safety aspects with clients and family.
- Public campaigns, for example about medication safety ‘Speak up’ and ‘It’s OK to ask’, mobilise and motivate the public to maintain an accurate medication list. The campaign starts with the message that such a list saves lives: patients are advised to keep such a list in a bag or wallet and tell relatives about it and to take this list with them to the professional to prevent medication errors. The campaign also includes a national media message that says that hospitals, pharmacists and professionals issue forms on which clients can set out their medication history.
- Clients and family are actively involved in:
  - client identification,
  - transition moments,
  - marking of area to be operated,
  - medication registration and in
  - infection controls.

Clients and family also receive information about:
- the risks of treatment and investigation,
- what the client himself can do to prevent risks,
- the incidents that the client must report,
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- alternatives to the chosen treatment method.
Clients and family receive supporting material (checklists, information folders).

Specific organisation initiatives
- Having clients interviewed about patient safety by hospital managers.
- The holding of family meetings and focus groups on patient safety following discharge.
- The performance of family satisfaction surveys in high-risk care provision.
- The encouragement of staff in the development of new forms of patient participation in patient safety.
- Setting the stage: ‘Consumer Affairs’ function. A member of staff facilitates the expansion of patient participation in patient safety, for example through peer-to-peer empowerment training of clients.
- The creation of a dialogue about patient safety as an education project for clients and staff, for which experienced clients and family are hired in.
- Setting up a Patient Safety Liaison system, which facilitates and supports the process of creating a culture in which team members, clients and family find it comfortable to talk about patient safety problems and concerns.
- Call First: Family Initiated Rapid Screening Team. The family is allocated a telephone line for if there is a change in the condition of the client. A nurse supervisor is present within 15 minutes. The feedback on the initiative is positive, but there is no research data available.
- The deployment of parents as safety monitors for children.
- The provision of good information to clients so that nurses allow the client to participate actively in the prevention of harm in chemotherapy.
- Clients learn to record their medication under the supervision of a professional. Clients make errors in the recording of medication more often than professionals.

Specific means of support (tools) used in care organisations
- Clients receive a ‘Partners in Safety’ brochure.
- Clients receive checklists with advice on their active role in patient safety.
- Clients are involved via checklists in the making of a good diagnosis.
- Educational material for clients with the emphasis on patient safety.
- The Medication Form: clients reconcile their own medication histories with identity, type of medication, dose, form of medication, dispensation form, time and route.
- Let clients watch a video on patient safety together with their relatives and provide information about web sites with educational material.
- Let clients check whether the professional washes his hands: children receive signs with a smiley on one side and a frowning face on the other.
- Invite clients to report their safety doubts using brochures, notice boards and meetings.

Specific public initiatives
- Include patient safety themes in general public education.
- In the US and Australia safety agencies have developed folders and fact sheets for clients with guides, tips and step-by-step plans for preventing errors. In this way the client becomes co-monitor of his care process and his own safety.

Specific practical research initiatives in organisations
- A list of 21 recommendations for older people for fulfilling a role of their own in the enhancement of their safety. What they want, can and actually do is considered. On this basis a training programme has been developed to improve the skills of the older people.
4.1.4 Knowledge of patient collectives with regard to patient safety

In the case of research into the question of interventions aimed at the public the literature focuses in particular on public campaigns. Both clients and professionals and organisations are reached in this way. The campaigns focus on: raising awareness of the risks, improving the relationship between professional and client and providing tips and tools for organisations, professionals and clients. Examples of public campaigns are:

Joint Commission
- ‘Speak Up’ campaign and materials.
  - Web sites with posters, questionnaires, brochures and videos for organisations to download and distribute
    - question builder to take with you into a consultation,
    - tips on site on how you can be more involved as a client,
    - links to other sources.

National Patient Safety Foundation
- ‘Nothing About Me, Without Me’
  - Call on organisations to involve client and family in the prevention and the reduction of harm if an error occurs.

National quality forum (2006)
- Development of a list of 30 safety tips for practice to reduce harm to the client. It also gives concrete examples of interventions at patient level in a specific treatment.

Safe Care Wisconsin (2005)
- ‘List it, Don’t Risk it (2008)’
- Partners for Advancing Health Care Safety was set up with the aim of helping clients enter into a relationship with professionals.

Interventions aimed at client councils relate to a strengthened advisory right of client councils in relation to patient safety. The interventions for patient representatives and patient collectives focus on a partnership between these organisations, with collective advice in the area of patient safety as a result.

4.1.5 Knowledge of evaluation and research into the effect of interventions

The literature reveals a small number of initiatives of local practical research on the evaluation and research into the effect of the role of the client. This practical research has positive results. It has been found that the involvement of clients leads to greater patient satisfaction and a positive organisational change. There are still no measurements of the actual effect of the interventions in the enhancement of patient safety, such as measurements of the effect of the patient himself keeping medication up to date or the effect of information material and tools for clients. Some practical studies do show that clients and family are good at spotting and reporting on adverse events, a lack of staff, best practices and behaviour of professionals.

No cross-organisation scientific research has been found in the literature, which specifically reports that (further) empirical research is needed into the impact and the importance of the five factors below and the interaction between them. The implementation of the role of the client also depends on these factors.

1. Client-related: knowledge of and opinions on patient safety,
2. Illness-related: phase and characteristics of the client’s illness,
3. Professional-related: knowledge of and opinions on patient safety,
4. Setting-related: characteristics of primary, secondary and tertiary care and elective or emergency clients,
5. Task-related: the characteristic of the intervention by clients.
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Practical research for example shows that lowly educated and unemployed male surgical clients are the least prepared to ask professionals challenging questions about their safety. In addition, the inviting behaviour of the specialist to ask questions also has an effect on asking professionals questions.

It has also been found that insufficient research has been done into the readiness, the possibility and the actual execution of interventions by clients, nor into how the client can fulfil his role in patient safety.

Effects of interventions that are currently known depend in part on the context in which the interventions have been introduced, for example, on the context of the country, the healthcare system, the different norms and values of clients and the different positions of professionals.

4.1.6 Knowledge of desirability and views of clients, professionals and policymakers about the role of the client in patient safety

What views do people have about the desirability of patient participation in patient safety and the fulfilment of that role? Policymakers in particular express views and wishes in this regard. A culture is needed in which the client becomes part of the healthcare system, so that he can make a contribution to the reduction of errors from his perspective. Involving clients in safety is part of a broader concept to involve clients in care. At the same time patient participation is only a small part of a greater drive to improve patient safety. Clients must only be involved if they are themselves both willing and able. A 'one-size-fits-all' approach does not work and attention is needed for diverse cultural opinions.

The patient perspective in patient safety remains neglected. Both clients and professionals are convinced that partnership of clients in the prevention of medical errors offers huge opportunities. Clients and families have the potential to play an important role in the prevention of medical errors, because they are physically present throughout almost the entire care process, can observe well and are able to understand inconsistencies and errors. They can serve as a buffer. The chronically sick for example become experts in their own illness and care and possess important contextual information. Patient safety however remains a core task and responsibility of the professional. The effects, limits and potential dangers of client participation require further study.

Clients and family may have a role in patient safety to the extent that they are willing and able to do so. Clients would like to be aware of the risks, so that they know what they can do themselves. Clients are often insufficiently informed however. In addition, psychological consequences of medical failings must be recognised. They must be communicated effectively and be based on what concerns the client. The partnership in this regard must be actively encouraged.

Clients are being admitted for less and less time, so the care is more fragmented and diverse. Initiatives must therefore also have an extramural focus. The moments of contact with professionals in practice are minimal. A client himself undertakes the greater part of the patient safety activities at home without any supervision by professionals. There are a number of possible roles that the client can take on:
- as an individual who experiences the positive and negative effects of safety,
- as an observer of quality indicators (decision aid in selecting provider),
- as a collective as a client representative.

Public education is needed to ensure that clients can acquire a role in the improvement of patient safety. The term patient safety is not yet as clear to the public as the term medical errors, but even the term medical errors still has limited scope in public circles.

The client’s view of safe care and the contribution he can make to it is not known and has not been assessed for value. The current assumption is that the client fits into the safety system that the provider has. The scope goes no further than what the organisation considers important. There is a lack of consensus about what clients can do about safety.
themselves, for example, about the involvement of clients in the description of what safe care is, the designation of safety indicators and the involvement in the strategy to comply with it. It is also possible to involve the client in improvement and research projects, the choice of interventions (include in guidelines and standards), giving access to tools for patient safety and information systems, Patient Incident Notifications and in the design of recovery strategies.

The current notifications of incidents in client care are no more than the tip of the iceberg. Clients can contribute to patient safety by monitoring their care and reporting adverse events that would not otherwise be discovered. Information, communication, effective reporting systems and joint medication histories are the key terms in this regard.

Clients find it difficult to let their voice be heard where errors are concerned. The attitude and the readiness of professionals to listen to and work with clients is a crucial factor in this. Clients have sometimes developed their own ways of dealing with risks. They do not always discuss it, because they take the view that this may affect the authority of professionals. Clients do not like reminding care providers of their responsibilities, as with the ‘hand washing’ example (4.1.1).

As previously indicated, the public needs to be informed about the concept of safe care and how a client can put it into practice himself. This requires a social assessment of objectives and priorities. A client also needs a safety agenda in which wishes and experiences of clients are recorded. Incentives such as financing and facilitation are needed to motivate clients (or their representatives) to participate in the safety agenda.

One condition however is that a patient safety culture is created within organisations. Professionals need skills in a supporting culture, so that they can start seeing clients as ‘partners in safety’. Motivation and training are needed to bring about this culture shift. Clients have not yet been asked by care organisations and professionals to participate in reducing errors. The discussion cannot start until clients notice that their alertness to important details is appreciated. Historically professionals have not yet, in part from a hierarchical viewpoint, had an open attitude to patient participation. The consequence of a proactive discussion about the role of the client in patient safety may therefore be negative.

4.1.7 Gaps in the development of a responsible role of the client in patient safety

There are a number of gaps in the development of a responsible client role in patient safety. The healthcare system is not yet geared to the client as a ‘partner’ in the care process. Professionals are still too little encouraged to inform clients about and to involve them in patient safety. The following gaps are mentioned:

In the organisation of care:
- a role model is lacking from the administration of care organisations,
- there is a limited scope for care: the area of attention is restricted to contacts with professionals and facilities,
- a culture of patient participation in the training of medical students is not yet a general good,
- a care system that is reliable and transparent is lacking. If a system is so, a greater confidence in professionals can arise.

The development of skills of the professional in:
- encouraging and inviting clients to participate,
- developing an effective ‘partnership’ between professional and client,
- creating support amongst professionals for the need of partnership,
- creating a dialogue between professional and client about the content of the partnership,
- using interventions in which ‘one size fits all’ does not apply. Interventions must be adapted to the specific (unique) client.
A serious commitment of clients. For this insight is needed into:
- the client perspective (values, knowledge, attitudes, needs, ideas, readiness),
- the issues with which clients want to be involved when it comes to their own safety,
- interventions that affect the readiness to be actively involved,
- the steps that clients can take to increase safety,
- opinions of professionals about the role of the client in patient safety.

The development of skills of clients with regard to:
- the conviction that individual actions contribute effectively to the patient's own safety,
- reducing barriers in behaviour and attitude to participation,
- increasing the self-confidence about being able to carry out actions,
- interventions for clients from cultural minorities:
  - knowledge of outcomes of patient safety 'partnership' initiatives for clients and families of cultural minorities with a language barrier,
  - the way in which professionals can involve cultural minorities,
  - suitable interventions for ethnic minorities.

The advisory report 'You work here safely or don't work here at all' by former Shell managing director Rein Willems underlay the patient safety section within the Dutch Better Faster pillar 3 programme (2005-2008). It is fairly remarkable that no consideration is given in this report to a possible role of the client in patient safety.
4.2 Web search

Various initiatives came to light in which clients acquire a role in patient safety. The sections below describe the type of interventions that have been developed in the Netherlands and other countries to date, what the interventions are aimed at in terms of content, from which country they originate, to what participation level the interventions relate and what the content is of the interventions. The interventions are also given in the Annex: Annex 1 contains a summary of the analysis of the interventions and Annex 2 a summary of the description of all the interventions found online.

4.2.1 Interventions in the Netherlands

In the web search a number of interventions were found that have been developed in the Netherlands. They are the patient safety card and the animated film of the same name ‘Help with your safe treatment’ and the information folder ‘Dare to ask. Help with safe care’.

The patient safety card ‘Help with your safe treatment’ is an initiative of the Dutch Patients’ Consumer Federation (NPCF), the National Expertise Centre for Nursing and Care (LEVV), the Order of Medical Specialists (OMS), the Isala Klinieken and the Utrecht University Medical Centre (UMCU) (2006). The card gives clients tips that they can use in communication with their professional for involvement in the safety of the treatment. They include such tips as: provide all the information that is important, keep on asking questions if you don’t understand something and follow instructions. Clients are also advised to talk to the professional if they think that something has gone wrong. Finally, clients are given the advice to take a family member or friend with them to the consultation. The patient safety card has been adopted by a number of hospitals and adapted to their own hospital style and preferred form. One hospital for example has depicted the card on place mats.

As a variant of the card the Sint Maartenskliniek has developed the animated film ‘Help with your safe treatment’. Clients are motivated to fulfil an active role during the treatment to prevent unsafe situations. The film is shown at the bed of admitted clients and encourages them to ring the bell whenever necessary.

The information folder ‘Dare to ask. Help with safe care’ is an initiative of the Isala Patient Safety Centre and the Zorgbelang Overijssel patient organisation (2008). The folder contains similar information to the patient safety card: tips for patients for contributing to safe care. General tips are given for during a consultation with the professional, such as take someone with you, make a list of questions and ask for time to ask questions. Specific tips are also given for contributing to safe care: provide all the information that is important, write down the medication you are using and discuss the course of your treatment. Clients are also advised to tell the professional whenever something does not go as expected and that they can complete a notification form in the event of complaints on the web site of the healthcare facility.

4.2.2 Interventions in other countries

The other initiatives originate from the UK, the United States and Australia. Altogether 21 different interventions were found and they are similar interventions to those in the Netherlands. For example, a fact sheet with 20 tips for clients to help prevent medical errors ‘20 tips to help prevent medical errors’ (AHRQ 2000) or the film ‘Be part of your care’, in which patients are told about the role they can play in their own safety (CCQ&PSI). There is also the ‘My medicine list’ initiative to support clients in making a medication history and having it with them (ASHP 2007).

An example of a different type of intervention is ‘Add patients, change everything’ (CAPS 2008), the purpose of which is the development of partnership between client and professional in which they work together on the prevention of medical errors. This is done by
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letting networks of clients and care professionals come together at, for example, workshop sessions.

4.2.3 Method of patient participation

As described in chapter 2, there are various ways in which clients (patients) can acquire a role in patient safety in the course of the care process:

- **Information**: the patient is aware.
- **Consultation**: the patient contributes to discussion and thinking.
- **Advice**: the patient advises.
- **Partnership**: the patient co-decides.
- **The patient has control**: the patient decides.

Figure 1 shows the way in which patients participate in the interventions that emerged from the web search. Far and away the most interventions from the web search are aimed at ‘information’: clients are involved in patient safety by means of information provision to the client about what safe care is and the role that they can play in it themselves. This may be in the form of a folder, brochure, online information or a film. They are usually national or regional campaigns in which information is provided in various ways.

Two interventions can be said to be about ‘consultation’. The first concerns ‘My Medicine List’, in which clients themselves contribute to a medication history. The second is an initiative for involving clients in the reporting of incidents by asking what has gone wrong and what the reason for it was.

Finally, there are two interventions aimed at ‘partnership’. These initiatives attempt to let professional and clients work together by working as a team for the improvement of patient safety. Consumer and patient organisations, networks of clients and networks of professionals for example are involved in these interventions. These parties are brought together to collaborate on an equal partnership between professional and client to improve patient safety. Detailed information about the way in which the parties work on this was not unfortunately found.

Otherwise advice was also given in a large number of interventions in addition to ‘information’. These interventions are contained in the ‘information’ category instead of ‘advice’. An example of this is a brochure with tips for professionals for involving clients in the maintenance of their own medication file by the patient. In this way the client has sight of all the medication and better understands which medication is needed for what. The professional checks whether the recording is happening correctly. This intervention falls into the ‘information’ category as it is particularly about information supply to the client and about the way in which professionals can do this. It is not about its actual (support in)
implementation. The term ‘advice’ means that professionals and clients have direct contact in the intervention and that the clients take on the role of adviser. No examples of this were found during the web search.

Most initiatives in which information is provided about safety and the role of the client therein are aimed at the clients themselves or at their family on the basis of the thinking that ‘an informed patient is the safest patient’. There is also information material available for professionals which explains what role clients can have and how they can support their clients in this.

4.2.4 Level of participation

The role of clients in the care process can take place at various levels (chapter 2):

- **Micro level**: points in the treatment process at which clients have the opportunity to exert influence on a safe course of their own care process.
- **Meso level**: as client representative in client councils in a facility/practice.
- **Macro level**: at national level through client associations, panels, umbrella organisations, etc.

![Figure 2: Level of participation in the interventions found](image)

Figure 2 shows that nearly all the interventions occur at micro level, because they focus on information provision to patients about the role they can play in the safety of their own care process. Two of the interventions that are not aimed at ‘information’ but at ‘partnership’ occur at macro level. They are initiatives in which clients and professionals cooperate on safe care (see also ‘Method of participation’).

4.2.5 Intervention content

The interventions were analysed for content. The summary in Annex 1 was compiled on the basis of the information from the web search. It provides insight in particular into the type of information provided in the interventions, in a number of which it has been shown that insufficient information is available to complete the Table.

The main elements to emerge in the interventions are:

1. Choice of the right healthcare provider.
2. Deciding together and the client is an active member of the care team.
3. The determination of the diagnosis.
4. Treatment:
   a. Discussion of the treatment with the doctor and ensuring that the client understands what is going to happen.
   b. Asking or continuing to ask questions in case of doubt or ensuring that the patient understands all the information
   c. Providing information about health condition.
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d. Having access to the research or treatment results.
e. Medication: providing for a list of all the client’s medication.
f. Medication: observing whether the client is receiving the correct medication.
g. Checking whether the professional has washed his hands.
h. Taking action if something seems not to be right.
i. Following instructions of professionals.

5. Taking someone to the hospital who can speak for the patient if he is himself unable to do so.

6. Discuss the treatment plan for at home on discharge.

7. The reporting of incidents.

Information on the above elements is provided in a (great) number of interventions. In some interventions it is indicated that it is important to choose the right healthcare provider. For example, choosing a hospital where the treatment is carried out more frequently and where experienced professionals work.

Several information sources for client and professional state that they are both part of the care team. The client must be an active member of it. Remarkably, the role of the client regarding the determination of the diagnosis only explicitly emerges in one intervention. In that intervention clients are advised to express doubts about the diagnosis and not to hesitate to ask the professional whether something else may be the matter.

Many elements in the interventions relate to certain aspects of the treatment: discussing the treatment with the professional and ensuring that the client understands what is going to happen. In this connection interventions also emerge in which a client can check with professionals whether they agree with each other about the treatment and whether care providers agree with one another about the treatment chosen.

A large number of interventions mention that clients must express their doubts, concerns and questions and must ensure that they understand the information received properly. Asking questions is seen as an important way for the client to acquire an active role, because the professional can devote attention to matters important for the client. The chance is then greater that clients understand what risks there are and what they can do in this themselves.

It is important that clients give the professional information about their health condition. They often have knowledge that the professional does not have. They can also help contribute to information being transferred between the different professionals they deal with.

Some interventions state that ‘no news is good news’ does not apply. Clients must ensure that they are aware of investigation results for example, so that they know what the matter is and what they can do themselves.

Nearly all the interventions include a part about the medication. In the first place the client is advised to provide a list of all his medication and have it available for the professionals. There are a number of tools available for drawing up a medication list yourself and for keeping it in your pocket. In the second place clients are encouraged to check that they receive the correct medication both in the hospital and when collecting the medication from the pharmacy.

Some of the advice relates to steps that clients can take in relation to their professionals. They are encouraged to check that the professional has washed his hands. Clients can also take action themselves, for example by warning the professional themselves if the drip is not running through or refusing breakfast offered if the client has to fast before an investigation. Clients are encouraged to follow advice and instructions of professionals, such as not going to the toilet independently, but asking for assistance to do so.

If a client is not himself able to understand information and/or ask questions, he will be advised to take someone with him to the healthcare facility who is able to do so. Clients are also encouraged to discuss the treatment plan for at home, so that risks at home can be
avoided as far as possible. Finally, the intention is that clients can report incidents in the event that something has gone wrong.

Figure 3 shows that most common patient safety elements relate to clarity about the treatment and the medication. In this way the client knows what is going to happen during the treatment, what medication he is using and that the professional needs the right information about his health status. It is regularly stressed that the client is part of the treatment team.

Figure 4 shows that one of the least mentioned elements in the interventions is the determination of the diagnosis. The analysis shows that the joint discussion of the diagnosis and the asking of questions by the client is only explicitly mentioned in one intervention. This could however be an element that belongs to obtaining clarity about the care process. The reporting of incidents, the checking of hand washing by professionals and the taking of actual steps also rarely come up, just like the choice of the right healthcare provider and the discussion of the treatment plan for at home.
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Figure 4: Least mentioned patient safety elements in the interventions found

4.2.6 Effectiveness of interventions

The online information on the interventions found in general provides limited insight into the way in which the interventions have been developed. For example, it is not always clear on the basis of what idea and in what way the interventions have been implemented. What the experiences and the effects are is also often missing.

In the web search a short publication did emerge about the experience with the patient safety card in the Netherlands. In the period 2005-2006 research was carried out by the NPCF in partnership with the LEVV, the OMS, the UMCU and the Isala Klinieken. The research was carried out amongst clients of the surgery, neurology and neurosurgery departments of the UMCU and the Isala Klinieken. The purpose of this research was to gain insight into the patient safety experienced (first measurement) and the usability and effectiveness of the card (second measurement). A total of 300 questionnaires were distributed to clients. The response was 70% for the first measurement and 41% for the second measurement. More than 90% of the respondents said that patient safety is a matter for everyone and that clients can contribute to it by ensuring that no errors are made. Many clients (82%) find the card a useful tool for bringing tips and suggestions to the attention of clients. Almost half say that they have actually used the tips and suggestions. 30% of the patients feel safer after reading the card and only for 6% of the clients does the card create an unsafe feeling. Half of the clients say that they now know better what they can do themselves about the safety of their treatment. The reaction of professionals to questions that clients ask is however crucial. Therefore a patient safety card guide that is suitable for professionals will be developed as a follow-up.
4.3 Interviews with experts

The semi-structured interviews with Dutch experts were conducted on the basis of a topic list (Annex 3). In the sections below the results of the interviews are described anonymously on the basis of the following sub-subjects that have been derived from the sub-questions drawn up for the preliminary study:

- Knowledge of the role of the client with regard to:
  - experiences and effects,
  - limitations, risks and influencing factors,
  - the desirability.

- Knowledge with regard to the role of the client in patient safety of:
  - interventions for individual clients,
  - patient collectives,
  - the effect of interventions.

- Views of clients and professionals about the role of the client in patient safety.

- Gaps in the development of a responsible role of the client in patient safety.

4.3.1 Knowledge of the role of the client with regard to experiences and effects

The first aspect of the activities, experiences and effects in the knowledge of the role of the client is the meaning of the term patient safety. What the definition entails depends on the health sector. In one sector the term patient safety means “preventing risks within given frameworks, such as medication use”. In care patient safety is more about “preventing people being put in too hot a bath or in strapping”. Patient safety is also about the behaviour of the client at home, because care is increasingly taking place extramurally. As a result high-risk domestic situations are occurring with regard to illness, equipment, and therapy loyalty.

The second aspect is the current closed culture with regard to the role of the client in patient safety. Clients are still inadequately informed during the treatment process and the care provision continues to be insufficiently transparent. The client is often still seen as a disorder that must be treated. A statement that covers the essence is: “if you go auditing, people will listen to you, but it is still unusual for people to listen to the patient”.

Within patient safety more attention is currently being given to the subsequent notification of (near) accidents, boundary-crossing behaviour and freedom-limiting measures. Little is as yet being done to encourage the input of the client to prevent incidents during the treatment process. Open communication between professional and client is crucial in this regard. An example that illustrates this concerns the admission of a child who was nearly given too high a dose of asthma medication. The parent, themselves a healthcare professional, wondered whether the dose was correct. The nurse reacted to the alertness of the parent by checking the medication. She did not subsequently discuss the near incident with the parent. Professionals do not yet readily talk about (near) incidents. Victim organisations also say that the honest and structural provision of information about incidents and recovery treatments is not yet a general good.

A more open culture in the discussion of incidents does seem to have arisen between professionals, for example in the case of the week. If a professional starts seeing a client as a partner in the process of care provision, the discussion of incidents may proceed more naturally.

In the case of both the professional and the client a culture shift to an open atmosphere is needed to increase the input of clients during the treatment process. This is in keeping with present-day society in which a role change of the professional group of the specialist is taking place because of the internet: “the knowledge of the doctor is slowly becoming general knowledge. The actions however remain unique and profession-specific.”
Professionals can learn to be open to the signals that the client and his family (or representative) expresses during the treatment process. Professionals can for example be trained in responding to questions that clients ask in (potentially dangerous) situations, in actively learning to ask for suggestions from the client and in showing that any comment by the client is welcome. Telling clients about what the care looks like, what the risks are and what the client himself can do in this ought to be a general good. For example, telling the client about what the consequences are if the client comes to the hospital not having fasted.

Clients can learn to ask questions about the care process and be critical towards the professional: "pay attention to whether things are going differently from expected and ask how things are".

The potential effect of the role of the client in patient safety is safer care by using the extra eyes and ears of the client who is the only one to experience the care process "from A to Z". The client can throw light on the care process from a different perspective and is also better informed through participation.

A possible side-effect of participation by the client is that a client becomes more anxious. Anxiety may for example occur if the client becomes aware of the risks in the care. It also seems that the anxiety increases if the client keeps being asked to identify himself with no explanation of why. Clients must not be overwhelmed with information: "don’t provide any information with which the client does not come into contact and only provide information when it is relevant". Anxiety may be further increased because the hospital is also a kind of haunted house: "your perception changes when you are a patient". The risk of anxiety does not however mean that information must be withheld.

4.3.2 Knowledge of the role of the client with regard to limitations, risks and influencing factors

In the discussion of the possible limitations in the role of the client in patient safety the question whether a role is suitable for all clients is key. It is also said that a contribution of the client must be voluntary.

"The role is currently neglected, because there is a conviction that the individual patient is a weak player because of the emotional involvement and the lack of knowledge as regards content and insight into the care system."

It is felt that a role depends on the type of illness and the level of education. The chronically sick can better be involved in patient safety, because they have greater knowledge of their illness and treatment. Acute clients have little knowledge of what is happening and want immediate help: "the health condition does not always allow the control to lie with the patient" (see also 4.3.3). The involvement of the client is certainly part of the process, but a professional cannot simply rely on the patient. Because of illness a client is not always clear-headed and in his anxiety may misunderstand a question. Therefore a client is not always a fully reliable partner in care. It is also said that this does not mean that the client cannot be involved. The client's answer must therefore be placed in the right context. Allowance must also be made for the fact that the client may be wrong. In the involvement of the client in the prevention of left and right transpositions it does sometimes happen that a client indicates the wrong body part. A contribution by the client serves as an additional safety net in patient safety.

Opinions vary about the potential risks that arise if the client acquires a role in patient safety. It is even suggested that there are not actually any risks at all. If both perspectives are involved in the care process, work can be done together on the treatment and risks can be prevented. The client can assess situations properly because he is present all the time. There is also talk of a common interest of professional and client: "it will prove very helpful to
both to go through the process correctly and quickly and both can contribute to preventing incidents”.

A great risk mentioned is that the responsibility may not be shifted to the client. The professional may start “relying” on the client if he is assigned a greater role. Again it is stressed that the client is an ‘additional safety net’. In spite of the fact that the client can play a role in patient safety the professional retains final responsibility. In mental health care this plays a part in medication policy for example.

It is also mentioned that the client and the professional have a shared responsibility. After all, the professional is reliant on the cooperation of the client for the result of the treatment. The question is whether the term “responsibility” really is the right one in this discussion of the subject.

An influencing, and perhaps also limiting, factor is that the client “sees himself as king in his own care process”, irrespective of other priorities that come into play. Finally, where influencing factors are concerned, respondents say that expectations are perhaps created that cannot be met. A contribution by the client in patient safety does not after all provide any guarantee of safe care.

4.3.3 Knowledge of the role of the client with regard to desirability

In the sections above it has implicitly emerged that a greater role of the client during the care process is desirable. In the interviews there is a positive response to the explicit question about the desirability of the role of the client in patient safety: “the role of the client is a necessity, not a desirability”. Patient safety is never at an optimum without a contribution by the client. The control should be more with the client, precisely because he is the only one who experiences the entire process and is able to see what goes wrong. “The patient must take the wheel. Sitting in the passenger seat is not enough. You have to explain where the brakes are. With the current system responsibilities are being removed, so the patient is sitting in the back seat.”

The client is a controller of his treatment process. However, he can only point things out if he knows what he can point out and if he is aware of the fact that a role is possible. The client must also participate actively in the entire care process on the basis of an equal role.

How the client can acquire a role is not yet clear. On the one hand it is said that interventions still have to be developed. On the other it is assumed that while more tools may be developed, the question is whether the client is so inclined. As Fred Lee puts it in his tour of the Netherlands (2009): “you can always develop more tools, but will they make it any more effective?”. Nor must the interventions frustrate the process such that the professional is unable to act swiftly and effectively.

Clients can become more involved in the development of care policy. A client is himself the most motivated to limit risks and possible consequences. In addition to the role of the client and the professional there is the role of managers: “set the right example, otherwise the subject is doomed”.

The discussion that emerges from the question whether a role of the client is desirable corresponds to the discussion in section 4.3.2 about whether a role is desirable for all clients. And here too it is said that the basis for safety is the relationship between the professional and the client. In care for example the dependence relationship of the client is very great: “you are not quick to criticise when you are entirely dependent on your care providers”.

On the one hand it is said that a role in safety is assigned to a select patient group. Not all clients are able to do so and not everyone takes a role seriously. The chronically sick and elective patients certainly want to have a role and are also increasingly accepting a role. An acute client is less empowered. Where information and attitude are concerned, the average client is not yet equipped to take a role in patient safety. On the other clients are a last verification moment for pointing out possible incidents. This can be used precisely to
promote the safety process. It is evident from the reporting of incidents by professionals that the reporting of incidents by clients produces additional information. Clients even seem to gain in confidence as they acquire greater influence. Only a small percentage of the clients say they feel unsafe if they acquire influence over their own safety (patient safety card survey August 2009).

If a client is able to participate, it is on the one hand a matter of using common sense: “the only thing that a patient can have at his disposal is common sense about what is happening. Taking account of the physical and mental condition of the patient.”

On the other it is a condition that the client knows what safe care is and what the role of the client entails. The information supply must be equipped for this by providing insight into the risks and into what the client can do himself to increase his safety: “you can in any event make the consumer more critical with regard to his care process”. The motivation will be high because “the patient considers his own safety very important”. But, do you want the client to be paying attention to everything? This question remains unanswered.

4.3.4 Knowledge of the role of the client in patient safety with regard to interventions for individual clients

There are still few interventions in the area of the role of the client in patient safety. The client may be involved in the primary process depending on his situation. In the consulting room it is a matter of the dialogue between the professional and the client. A suggestion is to devise a system in which consideration is given to whether important aspects of the life of the client are discussed at the consultation. If clients are also taught skills they can then take on their responsibility. A question that emerges is: “do you want to let the client contribute ideas at this level or do you want to use his unique hands-on expertise”. In a prospective risk analysis for example risks are assessed for each process step. The hands-on expertise of the client could be put to good use here. The perspective and the knowledge of the client can also be better utilised in the development of protocols, guidelines and criteria:

“in this regard you cannot apply n = 1. Patients must have the right skills and the ability to contribute ideas on subjects at an abstract level. They must be able to detach themselves from their own situation.”

What most common interventions are available in the Netherlands? What is striking is that the intervention most mentioned in response to this question is an intervention that was developed for professionals. In particular in secondary care and now with a further development to primary care: the Safe Incident Notification. This however is aimed at the phase after the treatment process: “you would however want to discuss minor incidents more often instead of incidents afterwards”. In the past the Safe Incident Notification has also been used for clients, but it seems that clients notify little. There has been no research into the reason for this.

If an incident has occurred you can inform clients properly about medical errors, their effect and the follow-up steps, legal options and financial concessions there are: “(psychosocial) reception of medical victims remains inadequate in the Netherlands”. A guide is in preparation for clients about dealing with harm. The establishment of an aftercare outpatients’ department for victims is another wish.

When asking about interventions used during the treatment process the patient safety card in care emerges. The card was developed by the NPCF and the UMCU Patient Safety Knowledge Centre and Isala Klinieken. This first initiative was adopted by the St Maartenskliniek and the Sint Franciscus Gasthuis. The card uses light-hearted cartoons to make the client aware that he is in a complex environment. The light-hearted pictures ensure that the client retains confidence in the healthcare. Hospitals take it over and give it their own slant. The card has now continued its development into primary care. The idea is also to develop a download centre for facilities with a “tinkering environment”. A question that has now arisen is how the card can be spread further afield (see also 4.3.6).
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The St Maartenskliniek has developed an animated film running in sync with the introduction of the card: “an instruction film over the bed of patients. Thought was given to how information can be provided about dangerous situations without prompting a sense of unease. This led to the use of animal figures that produce a cuddly feeling.” Similar initiatives are the DARE to ask film and folder.

Within the national Better Faster pillar 3 programme tools such as focus groups, mirror meetings and the mystery guest (2005-2008), in which patients are asked about their experience in care, have been used within patient participation. A patient folder with information about decubitus was also produced in this programme. In addition, patients cooperated on the prevention of decubitus by themselves also paying attention to turning on time. When the patient needed a change of position again was therefore made visible on a clock for the client and the professional.

Individual initiatives for example include that of a hospital at which there is a sign in the outpatients’ department with the question to patients ‘What has occurred to you?’. An as yet theoretical initiative for a client-oriented intervention is ‘MyMedication’, an information system for medication of the older patient with comorbidity that is updated by the client himself.

In care it is said that the initial tools are ‘Tell us’ and the discussion of the ‘Care living plan’ with the client. In the case of the former interviews are used to find out what the client experiences in the care provision. In the case of the latter, which is now mandatory, it seems to be more in the direction of the role during the treatment process.

The practical guide of the national SMS care programme has to date only said that it is important to involve the client in the care process.

There are plenty of ideas for possible interventions for the individual client. Existing interventions are also mentioned and interventions that are aimed at the professional:

Give explanation to the client about what patient safety means in general and what the client can contribute to it himself:
   o Give explanation of patient safety with reference to diagnosis treatment combinations.
   o Put guidelines and protocols into concrete terms.
      ▪ Make a list per treatment on which the most common items can be read in a few minutes.
      ▪ Say what very often goes wrong and what symptoms are a risk.

Give training to clients to ‘empower’ them:
   o Teach clients to draw up their own care plan.
   o Teach the chronically sick what risks there are and how they can respond to them.
   o Teach clients to be alert to what the professional expects of the client.

“Make the patient more up to it”:
   o Posters/cards/badges asking whether professionals wash their hands.
   o Make the client aware that he is allowed to ask questions and take a list of questions with him to the consultation.
   o Give tips: for example take a critical partner with you to the consultation.
   o Make a contribution to the safety of fellow patients in the room.
   o A television over the patient’s bed with film about patient safety.
   o A guide for the client: ‘what to do after an incident?’
   o A guide on ‘how do you prepare yourself for hospital admission?’

Clients/professionals/healthcare facilities:
   o Let clients write down ideas and frequently occurring items.
   o Actively ask patients in the room what occurs to them (while drinking coffee).
   o Distribute the ‘tip of the week’ and ‘safety rounds’ amongst clients as well.
   o Involve the client in existing procedures and the daily process.
During visiting hours bring in family/visitors and distribute folders to them too.

Professionals:
- Video training for professionals of transfer situations.
- Use the input of a client at the ‘case of the week’.
- Use stories of patients to create awareness.
- Ask as a professional whether the patient wants to be an instructor.

Healthcare facilities:
- Conduct patient surveys, even if they often give desired answers.
- Implement mirror meetings and include patient safety in them.
- Include a passport photo in the status of the patient for the confidence relationship.
- Share medication with a smock on.

(Indemnity)Insurer/government
- Include the role of the client in the contracts with healthcare facilities.
- Develop a system for the recording of events.
- Make a film for themes from the national SMS programme. Campaigns: everyone is a patient, even the professional!
  - Have professionals wear badges with the text:
    - ‘Can you make me better?’
  - PO Box 51 spots and SIRE:
    - “insist on your right as a patient” and
    - “cooperating with your care makes the care”.

4.3.5 Knowledge of the role of the client in patient safety with regard to patient collectives

In the question about knowledge of patient safety with regard to patient collectives it emerges that the role of client councils in healthcare facilities is important. Currently this role remains underutilised. The hands-on expertise of client councils can be utilised by involving them in the redesign of (daily) care processes and contributing ideas in advance about the policy of the healthcare facility. In the redesign of care processes the client can be taken as a starting point. It is important that client councils professionalise and that the healthcare facility cooperates with the facilitation of a client council. This can for instance be done by making clear what is expected of a client council and which persons can sit on it. In this way they can be a serious discussion partner. Education about patient safety and about a programme such as SMS care is needed to be able to contribute ideas to policy proposals. Client councils can be involved in the drafting of annual reports about incidents and complaints that have been notified and discuss them proactively with the management. Care administration offices can seek advice from client councils when contacting facilities.

Patient organisations can be involved at departmental level: seeking advice on the organisation of departments and on patient safety from their own hands-on expertise.

Consumer and patient organisations can also play a role by picking up signals and doing research from the patient’s perspective. Internationally the Netherlands seems to be leading the way in terms of client councils and patient collectives. The client in the Netherlands is currently active through national (victim) organisations. Victim organisations need a more structural and equal role and want to be involved in discussions about government policy, victims and the professional group itself. Their involvement in this preliminary study is seen as positive.
4.3.6 Knowledge of the role of the client in patient safety with regard to the effect of interventions

What is the effect of the said initiatives on the role of the client? What a number of respondents are surprised about is the existence of the Medical Treatment Contracts Act. It is strange that an Act is needed to oblige the professional to involve the client in the treatment process and to act safely in the process. The care should be safe on the basis of this ‘intervention’ alone. The role of victims may be greater by for example involving the client in the central medical disciplinary tribunal: “victim organisations can and should be a fully-fledged party in addition to the umbrella organisations if they are financially supported therein”.

Research into the effect of the role of the client has been done at the Patient Safety Knowledge Centre of the UMCU with the assistance of focus groups. It shows that the basis for patient safety is the relationship between professional and client. If this relationship is good, errors can be prevented. In fact in a good relationship fewer complaints arise if an error occurs, because the client then has confidence that the professional will work on the error. A conflict arises precisely at the point that a relationship is disturbed. Interventions aimed at the relationship between the professional and the client are needed to increase patient safety: “the basis of a measure is the relationship with the client, otherwise it has no effect”. The degree of therapy loyalty also depends on this relationship.

Different valuable ways of questioning the client, for example in mirror meetings, focus groups and by means of mystery guests, have been developed in the patient participation process within Better Faster pillar 3. Patient safety can be included as a subject in this. Mirror meetings on patient safety can also be carried out amongst professionals.

The pilot tests with the films shown to clients are experienced as pleasant and can be developed further into other sectors. The film can be shown at waiting moments in primary, secondary and tertiary organisations.

The NPCF is currently studying the effect of the patient safety card in hospitals, with the aim of putting the use of the card to better effect and continuing its development into primary care. Good implementation is crucial. The effect depends on the culture in a hospital and the awareness-raising by the card has so far been moderate. The information aspect requires further attention. If the card is not explained by a nurse it does not work. It is a tool for supporting communication and culture. There is also a version for professionals available. Some specialists say that they have no need of the card, because the Medical Treatment Contracts Act already provides for this. Professionals say that for a successful use interventions such as the card must be introduced on the basis of the Medical Treatment Contracts Act for example. Research into the effect of interventions on the role of the client has mainly taken place in care (see also 4.3.4).

4.3.7 Views of clients and professionals about the role of the client in patient safety

Where views of clients and care professionals are concerned, it is said that communication is important. Communication between professionals is still often inadequate. For a client it is not always clear what is or is not allowed. Clients can be invited more by professionals to make comments and to ask questions. At the Isala Klinieken it emerged that a ventilation system was not working properly thanks to the family of a client: “you can very well extend your hand to the patient”.

Professionals can also teach themselves more to seek coordination more often with fellow practitioners: “it is not by nature that you communicate with different professionals. The client may be more aware of this by checking it actively.”

Patient safety is teamwork. If the client is seen as part of the care team then the role of the client becomes more natural: he can express his lack of safety. The condition mentioned above however is that the confidence relationship between the professional and the client is good. In present care where care is seen as a ‘product’ because of market forces this is almost impossible.
"Is care a product or service? If care is a product, the buyer has no influence on the product. The characteristic of a service is that the quality is determined by the interaction between the client and the professional/producer."

In the year 2009 the thought that the professional is an authority still often prevails. The professional can change this by responding to the client as these initiatives show in his own safety or in that of a fellow client. He needs skills to be able to make the client “into an ally”. The professional can learn to go deeper into the person in front of him, placing him in the context of his environment: what does the illness and the medication mean for this patient?"

To invite professionals to do this they need insight and knowledge of the subject:

- Show good examples, including results and added value.
- Involve in the development of interventions.
- Have interventions tie in with existing systems such as the Medical Treatment Contracts Act.
- Show that involvement does not take more time and does not form a barrier.
- Show that the client is an additional verification in the care process.
- Give the client skills to learn to participate.
  - For example, let clients themselves explain what is going to happen.
- Learn to assess the self-management of the client.
- Develop and use communication skills:
  - ask open questions and listen carefully, client interaction,
  - create space in the anamnesis.

A culture shift by the professional, the client, the government and umbrella organisations is needed to give back the client his responsibility and independence. The current healthcare system is now organised with the best intentions so that the independence and responsibility of clients are reduced:

"you must prevent the patient surrendering his independence and responsibility at the front door. Take nothing over from the patient that he can do himself, but do not leave the patient to his fate either."

Health, Welfare & Sport must make it its work, because if that does not happen, the client will not feel he is being taken seriously: “it is crazy that there is not yet any mass mobilisation against healthcare and safety in the Netherlands”. 
4.3.8 Gaps in the development of a responsible role of the client in patient safety

There are still many gaps in the development of a responsible role of the client in patient safety: “there is a little of everything”. Developments are now under way at the beginning and end of the care process. The actual involvement of the client during the treatment process is not done much yet. The client is still insufficiently seen as a discussion partner. The opportunities that are currently available are still too little utilised. There is a lack of research into the effect of the pilots that there are. It is for instance unclear to what extent the client wants to have a role. A tip is actually to ask the client himself whether he wants to have a role and what this role may be. “The gut feeling of patients and families and possibly also of volunteers and cleaners is a large area for development”. One answer to the question of how a role can be designed is not possible. Patient safety ought in the future to be aimed at the implementation of tools from which the client can make a customised choice.

How the relationship between the professional and the client can be rendered is also not yet known. It remains a fairly abstract concept. Providing information about the aspects of an illness is good, but clients must not be frightened. In addition, the discussion of incidents is still overlooked. There is also the fact that “empowerment is a rude awakening if you are in hospital yourself”, because not all clients are able to express themselves adequately when they are unwell.

Greater openness can be created by putting the client centre stage and inviting the client. Insight must emerge into why things must be different. Interventions must be implemented from the perspective of both the client and the professional and it must be gauged whether it is also working through into a culture change. Working directly on an open culture is not after all effective. Campaigns may contribute to the enhancement of alertness and the stimulation of awareness. In this regard it is important that modern means of communication are used on the basis of a powerful marketing strategy. In this strategy cooperation and coordination are needed between the expert organisations and it is unimportant who the owner of an intervention is. It must become ‘hip’ to pay attention to safety. Professionals must also be made aware of interventions and must be involved in their development. Campaigns in combination with practical examples lead to the visualisation of effects and make the embedding in existing procedures easier: “it sounds very logical, but we’re not there yet”.

How gaps can be resolved remains the question. There is still a lack of skills. Information about the care and its safety aspects could be more transparent for clients, so that the client knows with what he is comparing healthcare facilities, what performance indicators entail and what he must look out for. Handles are needed for the professional about how he can actively involve the client. At the same time the care process can be organised more around the client, so that the care becomes more efficient and safer. The field is still clearly in development in this regard and research is still lacking. The danger however is that people will get bogged down in research: “get on and do it!” is therefore the advice.
4.4 Expert meeting

At the end of the study the results of the literature review, the web search and the interview session were presented to experts in the field. The purpose of this was to review the results and to set priorities for the follow-up patient safety programme. Most of the experts work in facilities that were also involved during the interview session. The results were reproduced for each research element in a PowerPoint presentation and explained in detail by three consultants. The experts had the opportunity to ask questions and make comments on the results found. Then a discussion of the results of the preliminary study took place between the experts in two groups. In the plenary feedback experts were finally asked what recommendations they wanted to make for the follow-up patient safety programme. The following recommendations emerged from this.

- For clients to be able to play a role in patient safety it is important to pay attention to the culture in the healthcare facility, before using ‘tools’. In a culture shift to give the client a role in patient safety awareness is needed of the fact that a role is possible. In the culture discussion it is crucial that the professional can actually take advantage of the role of the client and sees it as self-evident that the client can have a role.

- The reception of (former) victims and the recognition of errors to clients is necessary to create an open culture around medical errors. This is also necessary to design a role of the client in patient safety.

- Healthcare facilities should receive a quality mark for each department. The interaction between the professional and the client works preventively if it is about the prevention of errors. Victim organisations can also issue a quality mark.

- Transparency of the care provision is needed to let the client know what to expect. This may be coupled with quality systems that can be set up at a more detailed level than has so far been the case.

- The client can very well act as an adviser to the professional in his own care process. In this way the term responsibility is put in the right context. The client does not after all have final responsibility for his safety. The professional retains final responsibility for it.

- It is the task of professionals to let clients play a role in patient safety. To learn this professionals need support, such as training courses and time to reflect. A repertoire is needed for what to do in the consulting room.

- The role of the client in patient safety only works if it is used bottom-up. With the assistance of a pilot the forerunners can start and gain better insight into the effect. From here a start can be made with the facilitation of professionals to let clients take on a role in patient safety.

- An approach to setting down the role of the client in patient safety is the enlargement and investigation of good examples and continuing their development. This may be possible in combination with a nationwide government and healthcare facility campaign, to reach both the professional and the client.
Chapter 5 Conclusion and recommendation

In this chapter the recommendation for the implementation of the role of the client in patient safety in the follow-up patient safety programme in the Netherlands (5.2) follows on from the conclusion (5.1).

5.1 Conclusion

In the sections below an answer is given to the research questions on the basis of the literature review, the web search, the interviews with experts and the expert meeting.

5.1.1 Knowledge of the role of the client with regard to experiences and effects

A culture shift to an open culture in which the perspective of the client is involved is needed to give the client a role during the care process. An open culture starts with the relationship between the professional and the client. The client perspective provides an added value in the progress of the care process, because the client has a unique perspective on the care process that is supplementary for the professional. Supporting interventions are needed for the development of the role of the client that influence the relationship (and dialogue) between professional and client. The dialogue between professional and client starts with open communication about (near) incidents in which the client perspective can be better utilised. The unique perspective of the client must also be involved in the drafting of guidelines, protocols, care standards, patient safety policy and in the legislation and regulations. This may contribute to a transparent and reliable care system that is understandable and clear to clients and professionals.

A condition for the ability to fulfil a role is that the client knows what patient safety means, what risks there are and what he – just as for example in traffic – can contribute to the care process to enhance his safety. The client can make a contribution if he receives the right information and develops skills, so that his self-efficacy (the confidence in his own ability) is enhanced. In this way the client will dare to ask the professional questions and to report if the care process does not go as expected. To prevent the client becoming anxious it is crucial that the information and skills are offered at the right time in the right dose. For the professional it is important that in the dialogue with the client he receives signals from the client, he places the client in the context of his illness and invites him to participate in the dialogue.

5.1.2 Knowledge of the role of the client with regard to limitations, risks and influencing factors

This research shows that there are some limitations to the role of the client in patient safety. Not all the clients in cure and care can be expected to be willing and able to participate actively in their own care process to increase their safety. The client is after all vulnerable and emotionally involved. A role of a client is therefore always voluntary. For the professional the voluntary contribution of the client is an additional verification moment in the care process to prevent incidents.

There is a risk that the responsibility of the professional for the care process shifts to the client. The professional however retains final responsibility for the care process. It is therefore better not to speak about ‘responsibility’, but about an advisory or controlling role of the client in patient safety.

An influencing factor that comes into play in the role of the client in patient safety is that care provision remains a high-risk process. The involvement of clients will never therefore fully guarantee patient safety.
5.1.3 Knowledge of the role of the client with regard to desirability

The role of the client is a necessity, not a desirability. The perspective of the client is indispensable during the care process, because the client is the only one to go through the entire care process. And the professional is co-dependent on the client for the results of the care process.

The way in which the client can fulfil a role remains unclear and depends on the degree to which clients are willing and able to participate. It is important that clients become aware that they can fulfil a role in patient safety and that they are supported by a good information supply about patient safety and about choosing the right healthcare provider. And that they develop the right skills. For that matter this applies to the professional too. It is therefore important for both the client and the professional that they become aware of the fact that a role of the client is possible and that they both develop skills to fulfil the role. In this way the self-efficacy of clients and professionals in giving the client a role in patient safety grows.

5.1.4 Knowledge of the role of the client in patient safety with regard to interventions of individual clients

International interventions of individual clients occur mostly in cure. In Australia and in the US government campaigns in particular are carried out in partnership with healthcare facilities. Their purpose is that both the professional and the client acquire awareness of and insight into the effect of interventions. The campaigns mainly relate to interventions aimed at the client and his family or representative. They are still too little aimed at the professional and too little use is still made of the perspectives of the professional and the client in the development of interventions.

National interventions such as the (variants of the) patient safety card are also aimed at the involvement of clients in the secondary care process. The card has now continued its development into primary care. It is important to take account of the healthcare sector in which the safety of the client is at issue in the information about patient safety.

The (inter)national interventions about the role of the client in patient safety are currently aimed in particular at telling the client what patient safety is and what role the client can play in it himself. The relationship between professional and client is however crucial for the effect of a safety intervention. It is therefore important that not only is the client supported in his role, but also that the professional is supported in the involvement of the client in patient safety.

5.1.5 Knowledge of the role of the client in patient safety with regard to client collectives

The Netherlands seems to be leading the way where the role of client councils, patient associations and victim organisations is concerned. The role of the client councils in healthcare facilities is currently underutilised however. The professionalisation and facilitation of client councils, patient associations and victim organisations make it possible to involve the perspective of the client in the (annual) safety policy of healthcare facilities and redesign of care processes. A strengthened advisory right is needed and training and education on patient safety to optimise the role of client collectives. An integrated approach by all the organisations is needed to implement this subject successfully. In this approach it is important that consideration is given to the way in which all the parties jointly put the right interventions on the market.
5.1.6 Knowledge of the role of the client in patient safety with regard to the effect of interventions

(International) research into the effect of interventions with regard to the role of the client in patient safety is limited. The effect of interventions depends on the healthcare system, the culture and the norms and values of professional and clients. A ‘one size fits all’ implementation of the role of the client in patient safety is not possible. The implementation of the role in fact depends on five context factors: the specific client, the illness, the professional, the setting and the type of safety behaviour that the client exhibits. Further research into the impact of these factors is desirable.

In August 2009 an NPCF study into the effect of the use of the patient safety card in hospitals was published. That study, together with this preliminary study, offers a basis for making a start on a further implementation of the role of the client in patient safety. The linking to existing initiatives, their continued development, the researching of the effect of (new) interventions and the simultaneous banking on innovation of interventions significantly increase the chance of a sustainable effect. It is crucial that the client perspective and the perspective of the professional are involved in the (continued) development of interventions. The measurement of the effect of interventions then makes it possible to evaluate whether a culture shift to the involvement of the client in an open dialogue is actually taking place.

5.1.7 Views of clients, professionals and policymakers about the role of the client in patient safety

Professionals and clients are still only aware to a limited degree that the client can be part of the care team. Patient safety is after all teamwork. For both parties insight is needed into the effect of the role by showing good examples. Awareness and insight are achieved if the perspective of the client and the professional is involved in an open dialogue between professional and client at micro, meso and macro levels. And if this is supported by the system of legislation and regulations. Only then is the client able to make a contribution to his safety during the care process as an adviser or controller.

5.1.8 Gaps in the development of a responsible role of the client in patient safety

The gaps in the development of a role of the client in patient safety relate to a number of aspects. The present organisation of care is still insufficiently transparent and reliable. There is also a lack of insight into the degree to which clients are willing and able to play a role in patient safety. And there is still insufficient attention to the development of skills for professionals and clients. They both need awareness, self-efficacy and skills to give the client a role in patient safety. After all, the dialogue in the relationship between the professional and the client is set in motion in this way. The motivation of professionals is the guiding principle for the support and encouragement of clients to play a role in patient safety. The recommendation pallet for the implementation of the role of the client in patient safety (section 5.2) is based on the relationship between professional and client.
5.2 Recommendation

The results in chapter 4 and the conclusion in section 5.1 lead to a recommendation in this section. The recommendation pallet to ZonMw has been set out in Figure 5. In it the frameworks have been outlined that are important for a durable implementation of the role of the client in patient safety. Within these frameworks sufficient space has been created for ZonMw to further structure the follow-up patient safety programme.

The white centre spot symbolises the essence for the development of the role of the client in patient safety: the relationship between the professional and the client. The dialogue between professional and client is crucial in this. Both the professional and the client first of all need awareness of the fact that a role of the client is possible. They also need self-efficacy (the confidence in their own ability) and skills to be able to give the client a role. The white centre spot forms the sum total of the surrounding colours, which symbolises the integrated approach needed to help influence the relationship between professional and client:

1. **Client councils and client collectives** can only fulfil a greater role in giving the client a role in patient safety if they can professionalise and if they are facilitated. Client councils can be further involved in the policy and primary (redesign) of care processes with regard to the fulfilment of the role of the client in patient safety. For client councils a strengthened advisory right is important for its implementation in addition to education about the role of the client. Client collectives can start collaborating more, while victim organisations can play a role in the reception and aftercare of (former) victims.

2. The fulfilment of the role depends on the specific client (knowledge and opinions), the illness (phase and characteristics), the professional (knowledge and opinions), the setting and the type of safety behaviour that the client exhibits. Further research is needed into the impact, the importance and the interaction of these context factors.

3. **Effect research** is needed to study existing initiatives for effectiveness and then to continue their development and disseminate them. In addition, new initiatives may arise from research and continued development.

4. A **national information and knowledge centre** for all parties in care with public information on the role of the client in patient safety is needed to further implement the role of the client. Tools and education with regard to the subject will also be developed at this centre.

5. The development of a training programme for care organisations aimed at leadership, culture and structure in the form of a **patient safety officer programme** will contribute to the skills of professionals and organisations. In it the evaluation and optimisation of the programme is important for the further development of the role of the client.

6. Evaluation and optimisation is also important within the legislation and regulations. Within the current **legislation and regulations** evaluation research is needed into the role of the client. In this way compliance with the legislation and regulations can be optimised.

7. Involving the insight of the client in guidelines, indicators and care standards and in the drafting and monitoring of indicators leads to a more **transparent and more reliable care system**. A transparent and reliable care system also needs the range of choices of the care being made clear and understandable to the client. Finally, the discussion of incidents with clients contributes to a transparent and reliable care system.

This integrated approach for a durable implementation of the role of the client in the follow-up patient safety programme is shown in Figure 5 in the form of a colourful recommendation pallet.
The role of the client in patient safety
a necessity, not a desirability

Figuur 5: Recommendation pallet for the integrated approach for the implementation of the role of the client in patient safety (Illustrations: E. van ‘t Klooster).
The role of the client in patient safety
a necessity, not a desirability

<table>
<thead>
<tr>
<th>Patient board</th>
<th>Context factors</th>
<th>Intervention studies</th>
<th>Institute for information and knowledge</th>
<th>Laws and regulations</th>
<th>Healthcare systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionalize &amp; facilitate</td>
<td>Research &amp; insight</td>
<td>Developing &amp; innovation</td>
<td>Information to the public about the role of patients in patient safety</td>
<td>Evaluate &amp; optimizing</td>
<td>Transparency and making reliable</td>
</tr>
<tr>
<td>- Involvement in policy and primary health care processes</td>
<td>- Patient related</td>
<td>- Existing intervention studies</td>
<td>- Tools and educational programs to engage patients in patient safety</td>
<td>- Studies about the role of patients in patient safety</td>
<td>- Involve patients’ perspective in guidelines and care standards</td>
</tr>
<tr>
<td>- Education</td>
<td>- Illness related</td>
<td>- By developing and disseminating existing interventions</td>
<td>- Patient safety advisory</td>
<td>- Optimizing compliance with laws and regulations</td>
<td>- Involve patients in developing indicators</td>
</tr>
<tr>
<td>- Patient safety advisory</td>
<td>- Healthcare professional related</td>
<td>- Create new initiatives</td>
<td></td>
<td></td>
<td>- Transparent &amp; understandable indicators for patients</td>
</tr>
<tr>
<td></td>
<td>- Setting related</td>
<td></td>
<td></td>
<td></td>
<td>- Making choices in healthcare understandable for patients</td>
</tr>
<tr>
<td></td>
<td>- Task related</td>
<td></td>
<td></td>
<td></td>
<td>- Discussing incidents</td>
</tr>
</tbody>
</table>

Patient collectives
- Professionalize on patient safety
- Encourage collaboration between healthcare organizations
- Facilitate their role (also financial)
- Care and aftercare (older) healthcare victims

Patient safety officer program
- Evaluate and optimizing
- Training program for healthcare organizations: leadership, culture and structure

CBO Utrecht December 2009

EvdS/EP/YS
The role of the client in patient safety
a necessity, not a desirability

Literature


Cesta, T.G. 2006. ‘Ambulatory Care Quarterly. Joint Commission's 2007 National Patient Safety Goals will revamp emergency department nursing practice: new goals require you to involve patients in their care, give medication list on discharge’. Hospital Case Management 142-144.


The role of the client in patient safety
a necessity, not a desirability


Unruh, K.T. & W. Pratt. 2006. ‘Patients as actors. The patiënt's role in detecting, preventing, and recovering from medical errors’. International Journal of Medical Informatics 76:236-244.


Glossary & abbreviations

Adverse event
“An unintended outcome arising through the act (omission) of a care provider and/or through the care system with harm for the patient, so serious that there is a temporary or permanent limitation, extension or intensification of the treatment or death of the patient (NIVEL 2007)”.

Client/patient/consumer
Anyone who uses the healthcare system.

Client collective
Organisation(s) (national/regional) that represent client (groups), including victim organisations.

Client council
Representation of clients in a healthcare facility that looks after the client interest.

Family/representative
The immediate social environment of the client.

MIP
Patient Incident Notification

Patient safety
“The (almost complete) absence of (the chance of) harm (physical and/or mental) inflicted on the patient as a result of the failure of care providers to act according to professional standards and/or failings of the healthcare system. The basic principle is the pursuit of safe system design, so that errors are prevented or no longer lead to (irreparable) harm (NIVEL 2007)”.

Professional
The care provider in the healthcare system (specialist, family doctor, (district) nurse, etc).

Harm
“A detriment for the patient that because of its severity leads to extension or intensification of the treatment, temporary or permanent physical, mental and/or social function loss, or to death (NIVEL 2007)”.

Self-efficacy
The belief (confidence, motivation) in your own abilities to achieve given outcomes that have an impact on your own life (Bandura, 1994).

VIM
Safe Incident Notification
### Appendix 1  Web search: intervention overview (method of participation and level and intervention content)

<table>
<thead>
<tr>
<th>Intervention/activity</th>
<th>Method of participation</th>
<th>Target group</th>
<th>Participation level</th>
<th>Intervention content</th>
</tr>
</thead>
<tbody>
<tr>
<td>'Help with your safe treatment' patient safety card</td>
<td>Information</td>
<td>Patient (and/or family)</td>
<td>Micro</td>
<td>Discontinue; discuss understand course; give info about state of health; take action if something is not right</td>
</tr>
<tr>
<td>'Help with your safe treatment' film</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
</tr>
<tr>
<td>'Dare to ask. Help with safe care'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
</tr>
<tr>
<td>'5 steps to safer healthcare'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
</tr>
<tr>
<td>'Ways you can help your family prevent medical errors'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
</tr>
<tr>
<td>'20 tips to help prevent medical errors'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
</tr>
<tr>
<td>'20 tips to help prevent medical errors in children'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
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<tr>
<td>'Designing consumer reporting systems for patient safety'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
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<tr>
<td>'P.I.N.K. Patient Safety Video' (video content unknown)</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
</tr>
<tr>
<td>'Involve patients in safety initiatives'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
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<tr>
<td>'Involve patients in medication checks'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
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<tr>
<td>'Involve Patients in administering their own medications'</td>
<td>Information</td>
<td>Professional</td>
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<td>Take action if something is not right</td>
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<tr>
<td>'Have Patients Maintain Their Own Medication'</td>
<td>Information</td>
<td>Professional</td>
<td>Micro</td>
<td>Take action if something is not right</td>
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</tbody>
</table>

1. This refers to the self-administration of medication
2. This refers to the self-management of a medication file
Role of the patient in patient safety
a necessity, not a desirability

<table>
<thead>
<tr>
<th>Administration Record*</th>
<th>10 tips for safer health care. What everyone needs to know</th>
<th>X</th>
<th>X</th>
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<tr>
<td>&quot;Stand up for Patient Safety&quot; (insufficient access to content information)</td>
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<td>&quot;Ask Me3&quot;</td>
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<td>&quot;Speak Up&quot; Program</td>
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<td>&quot;List it. Don't risk it.&quot;</td>
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<td>&quot;My Medicine List&quot;</td>
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<td>&quot;Partners for Safety&quot;</td>
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<td>&quot;Be part of your care&quot; film</td>
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<td>&quot;Patients for Patient Safety&quot;</td>
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<tr>
<td>&quot;Add Patients, Change Everything!&quot;</td>
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<td>&quot;Taking Charge of Your Healthcare: Your Path to Being an Empowered Patient&quot;</td>
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<tr>
<td>&quot;Your role in medicine safety&quot;</td>
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</tbody>
</table>

* Addition in this regard is identifying the right person
### Appendix 2  Web search: intervention overview (initiators and intervention content)

<table>
<thead>
<tr>
<th>Intervention/activity</th>
<th>Initiator</th>
<th>Intervention type</th>
<th>Description</th>
</tr>
</thead>
</table>
| 1. 'Help with your safe treatment' patient safety card | Initiative of Netherlands Patient Consumer Federation (NPCF), National Nursing and Care Expertise Centre (LEVV), Order of Medical Specialists (OMS), Isala Clinics Zwolle and University Medical Centre Utrecht (UMCU) (2006). E.g.: [www.npcf.nl](http://www.npcf.nl) | Card (2 pages) | The 'Help with your safe treatment' patient safety card gives patients tips they can use in communicating with their care provider for involvement in the safety of the treatment. Tips:  
- Give all the information about your state of health  
- Say if there is something you do not understand  
- Discuss the course of your operation beforehand  
- Write down the medicines you are taking  
- Ask questions if the medicines look different from what you expect  
- Follow the instructions and advice carefully  
"If you think something has gone wrong, discuss it with your care provider. Question: What happened? How could it happen? What are the consequences for me, now and in the future? What is being done about it? If necessary, involve a family member or friend in this discussion." |
| 2. 'Help with your safe treatment' film | Sint Maartenskliniek (2007) [http://www.maartenskliniek.nl/nieuws/persberichten/1937889/](http://www.maartenskliniek.nl/nieuws/persberichten/1937889/) | Film (5 min) | An animated film in which patients are encouraged to take an active role during treatment to prevent unsafe situations. The film is shown at the bedside of admitted patients and encourages them to ring the bell whenever they need to.  
Content:  
- give all the information that is important for your treatment (such as allergies)  
- keep on asking if there is something you do not understand  
- ring the bell if you think something is not right (e.g. refuse breakfast if you have to fast, ask questions if your medicines look different)  
- follow instructions and ask for help |
| 3. 'Dare to ask. Help with safe care' | Isala Patient Safety Centre and Zorgbelang Overijssel (2008) [www.centrumpatientveiligheid.nl](http://www.centrumpatientveiligheid.nl) | Folder (2 pages) | Tips for patients on contributing to safe care. General tips for a discussion with care provider:  
- Take someone with you to an important discussion.  
- Make a list beforehand of what you want to ask.  
- Ask questions that start with who, what, where, when, why or how.  
- Ask for time for your questions! Make a new appointment if necessary.  
Help with safe care, ensure that you receive the right treatment:  
- Give all the information about your state of health  
- Say if there is something you do not understand  
- Write down the medicines you are using  
- Discuss the course of your treatment  
- Ask questions if anything is different from what you expect  
- Follow the instructions and advice carefully  
Tell your care provider if you feel something is not as it should be. You can also complete a notification form on the website |
<p>| 4. &quot;5 steps to safer healthcare&quot; | Agency for Health Care | PDF (1 slide) | Tips for patients for safe care: |</p>
<table>
<thead>
<tr>
<th>5.</th>
<th>&quot;20 tips to help prevent medical errors&quot;</th>
<th>Agency for Health Care Research and Quality (AHRQ) (2000)</th>
<th>Fact sheet (4 pages)</th>
<th>Information for patients on medical errors and the role they can themselves play to prevent them:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Be an active member of the care team</td>
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<tr>
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<td>Medication:</td>
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<td>- tell the doctor which medicines you are taking</td>
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<td>- tell the doctor about allergies and side effects that you have had</td>
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<td></td>
<td>- check that you can read the prescription properly</td>
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<td>- ask for information about the medication</td>
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<td>- when collecting the medicines check that they are the right ones</td>
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<td>- ask questions about information leaflet/label in the event of uncertainties</td>
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<td>- ask the pharmacist about how to measure out liquid medication</td>
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<td>- ask for written information about side effects</td>
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<td>Hospital admission:</td>
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<td>- choose a hospital where many patients have undergone the treatment that you need</td>
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<td>- ask all the professionals with whom you have contact whether they have washed their hands</td>
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<td>- on discharge ask about the treatment plan for at home</td>
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<td>Operation:</td>
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<td>- check that you and the doctors agree on what precisely is going to happen</td>
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<td>Other tips:</td>
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<td>- let someone know if you have any doubts</td>
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<td>- ensure that one person is responsible for your care process</td>
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<td>- ensure that all the professionals involved in your care have the right information</td>
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<td>- ask a family member or friend who can speak for you if you are unable to do so yourself</td>
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<td>- check why a test or treatment is necessary</td>
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<td>- ‘no news is good news’ does not apply in the case of a test; ask for the results</td>
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<td>- learn about your complaint by asking doctors, nurses and other sources for information</td>
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<td>- Be an active member of your child’s care team</td>
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<td>Medication:</td>
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<td>- tell the doctor what medicines and diet your child is having and what his/her weight is</td>
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<td>- tell the doctor about allergies and side effects that your child has had</td>
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<td>- check that you can read the prescription for your child properly</td>
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<td>- ask for information on the medication for your child</td>
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<td>- when collecting the medicines for your child check that they are the right ones</td>
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<td>- ask questions about information leaflet/label in the event of uncertainties</td>
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<td>- ask the pharmacist about how to measure out liquid medication for your child</td>
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<td>- ask for written information about side effects</td>
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<td>Hospital admission:</td>
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<td>- choose a hospital where many children have undergone the treatment that your child needs</td>
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<td>- ask all the professionals who have contact with your child whether they have washed their hands</td>
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<td>- on discharge ask about the treatment plan for at home</td>
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<td>Operation:</td>
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### Role of the patient in patient safety

a necessity, not a desirability

- check that you and the doctors agree on what precisely is going to happen with your child

Other tips:
- let someone know if you have any doubts
- ensure that one person is responsible for your child’s care process
- ensure that all the professionals involved in the care for your child have the right information
- ask a family member or friend who can speak for you if you are unable to do so yourself
- check why a test or treatment is necessary
- in the case of a test ask when the results will be available
- learn about your child’s complaint by asking doctors, nurses and other sources for information

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<td>Tips for (family members of) patients for safe care for themselves and family members.</td>
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<td>What can you do?</td>
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<td>- tell the professionals important things about your health</td>
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<td>- ask questions</td>
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<td>- take decisions about your care in conjunction with the professionals</td>
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<td>What can you do to ensure that you have the right medication?</td>
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<td>- take all of your medication with you to your doctor</td>
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<td>- tell the doctor if you have any allergies</td>
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<td>- check that the prescription is legible</td>
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<td>- on collection of the medicines check that they are the right ones</td>
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<td>What can you do to ensure that you are taking the right amount of medication?</td>
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<td>- Ask your doctor questions about this (how often, how much, when, how to take, how to measure out, etc.)</td>
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<td>What can you do to get better again quickly?</td>
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<td>- ask the professionals you are dealing with if they have washed their hands</td>
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<td>- pay attention to your diet and ask the doctor which food you are better off not eating</td>
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<td>What can you do to ensure that the right part of the body is operated on?</td>
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<td>- ask your doctor what is going to happen during the operation</td>
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<td>- ask your doctor if he has done this operation often</td>
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<td>- ask your doctor if he can mark the part of the body</td>
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<td>The main way to prevent medical errors is to talk. Talk to your doctor, nurse and other professionals. Bring a family member or friend with you who can help.</td>
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<td>Project for developing a system in which patients can report incidents. Patients can be an important source for patient safety. Information from the patient’s perspective is complementary to other reporting systems. Reports by patients provide greater insight into the causes of medical errors and can support the development of methods for quality improvement. The project is being implemented with a technical expert panel, patient focus groups, interviews with stakeholders, a study of the practice and a literature search. The project will be completed in September 2010.</td>
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<td></td>
<td>Video supplementing existing initiatives (usually folders) for patients as information, support and empowering to participate in safety of care.</td>
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<td>Short animation shown at the bedside. Places the patient at the heart of the care team and emphasises</td>
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<td>No.</td>
<td>Title</td>
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<td>Tips on IHI website</td>
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<td>10</td>
<td>“Involve patients in safety initiatives”</td>
<td>Institute for Healthcare Improvement (IHI) (start date unknown, currently online)</td>
<td><a href="http://www.ihi.org">www.ihi.org</a></td>
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<td>11</td>
<td>“Involve patients in medication checks”</td>
<td>Institute for Healthcare Improvement (IHI) (start date unknown, currently online)</td>
<td><a href="http://www.ihi.org">www.ihi.org</a></td>
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<td>12</td>
<td>“Involve Patients in Administering Their Own Medications”</td>
<td>Institute for Healthcare Improvement (IHI) (start date unknown, currently online)</td>
<td><a href="http://www.ihi.org">www.ihi.org</a></td>
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<td>13</td>
<td>“Have Patients Maintain Their Own Medication Administration Record”</td>
<td>Institute for Healthcare Improvement (IHI) (start date unknown, currently online)</td>
<td><a href="http://www.ihi.org">www.ihi.org</a></td>
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### Role of the patient in patient safety

*a necessity, not a desirability*

- be actively involved in your own care process
- express doubts or concern
- learn more about your situation and treatments
- ensure that you have a list of all your medication
- ensure that you understand your medication
- ensure that you receive the results of tests or procedures
- discuss the options if you have to be admitted
- ensure that you understand what is going to happen
- ensure that you and your professionals agree on the treatment
- before you leave the hospital, ask your care professional to explain the treatment plan for at home

| 15. “Stand up for Patient Safety” | National Patient Safety Foundation (NPSF, USA) (2002) [http://www.npsf.org/hp/su/](http://www.npsf.org/hp/su/) | Programme | The “Stand Up for Patient Safety Program” provides materials and sources to support patient safety initiatives in care institutions. Part of this is the involvement of patients and family as partners, through communication and transparency. Content information on the latter not found.

| 16. “Ask Me3” | Partnership for Clear Health Communication - National Patient Safety Foundation (NPSF, USA) (year unknown) [http://www.npsf.org/askm e3/](http://www.npsf.org/askm e3/) | Brochure (2 pages) and poster | Ask Me 3 is an initiative aimed at improving communication between professional and patient. Good communication is crucial for good and safe care provision. Patients can download a brochure and a poster with three questions that patients can put to professionals. In the brochure there is room to write down the answers the professionals give to the three questions.

Three questions:
1. What is my main problem?
2. What can I do about it?
3. Why is it important for me to do this?


- Speak up if you have questions or concerns. If you still don’t understand, ask again. It’s your body and you have a right to know.
- Pay attention to the care you get. Always make sure you’re getting the right treatments and medicines by the right health care professionals. Don’t assume anything.
- Educate yourself about your illness. Learn about the medical tests you get, and your treatment plan.
- Ask a trusted family member or friend to be your advocate (advisor or supporter).
- Know what medicines you take and why you take them. Medicine errors are the most common health care mistakes.
- Use a hospital, clinic, surgery center, or other type of health care organization that has been carefully checked out. For example, The Joint Commission visits hospitals to see if they are meeting The Joint Commission’s quality standards.
- Participate in all decisions about your treatment. You are the center of the health care team.

Speak Up Initiatives:
- Help prevent errors in your care
- Help avoid mistakes in your surgery
- Information for living organ donors
## Role of the patient in patient safety

a necessity, not a desirability

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<td>- Five things you can do to prevent infection</td>
<td>- Help avoid mistakes with your medicines</td>
<td>- What you should know about research studies</td>
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<tr>
<td>- Planning your follow-up care</td>
<td>- Help prevent medical test mistakes</td>
<td>- Know your rights</td>
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<tr>
<td>- Understanding your doctors and other caregivers</td>
<td>- What you should know about pain management</td>
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These initiatives consist of brochures (2 pages) with information and tips. The tips are usually aimed at for instance:

- What do you have to know about your treatment?
- Who is responsible for the safety of your care?
- What information about your health is important for your care provider?
- What questions can you ask?
- What can you pay attention to? (e.g. right body part marked, right medication, etc.)

### 18. “List it. Don’t risk it.”
Safe Care Wisconsin (USA) (2005)

www.safecarewisconsin.org

Initiative (in State of Wisconsin) for making and carrying a medication list by patients

Information for patients about the importance of making a medication list and carrying it with you in your wallet. Material for compiling and printing a list.

### 19. “My Medicine List”
American Society of Health-System Pharmacists (ASHP) and National Transitions of care coalition (NTOCC) (2007)

www.ashpfoundation.org

Folder

A folder for patients with tips for compiling a medication list.

### 20. “Partners for Safety”
“Be part of your care” film
Cleveland Clinic Quality & Patient Safety Institute (year unknown)

http://my.clevelandclinic.org/about/safety/partners_safety.aspx

Film and online tips

Information for patients and family for playing an active role in safe care. The “Be part of your care” film is for patients and is played on a television screen in the hospital room. There is a film for adults and another for children. Online tips for patients:

Be involved in your care:
- take part in all decisions about your treatment
- say if you have any specific needs
- ask a friend or family member to go with you if you are unable to participate actively yourself
- you are the centre of attention of the care team!

Say if you have any doubts or concerns:
- you can put questions to anyone involved in your care
- write down questions for your next visit

Identify yourself:
- check that the professional asks for your name and date of birth
Role of the patient in patient safety

a necessity, not a desirability

- do not hesitate to inform the professional if you think that he is confusing you with somebody else

Ensure that professionals make clear what they are going to do before the procedure starts:
- remind professionals that they must wash their hands

Take a medication list with you

Tell the doctor about your allergies and side effects you have had
- know what medicines you are using and what possible side effects are
- ask questions about the medicines that are prescribed

Being involved is worth the trouble!
- taking an active role has many advantages
- the professionals appreciate your involvement

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<td><a href="http://www.who.int/patientsafety/patients_for_patient/en/">http://www.who.int/patientsafety/patients_for_patient/en/</a></td>
<td>The purpose of “Patients for Patient Safety” (PFPS) is the improvement of patient safety in all health care settings in the world by involving consumers and patients as partners. PFPS works with networks of patients, consumers, professionals and patient organisations to support patient participation in patient safety.</td>
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<td></td>
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<td><a href="http://www.patientsafety.org/">http://www.patientsafety.org/</a></td>
<td>CAPS is seeking a partnership between consumers and care professionals to create health care systems that are safe, patient-focused and fair.</td>
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<td>The “Add patients, change everything!” initiative consists of workshops of local partners of CAPS that are involved in community-based consumer involvement. The aim is to develop sustainable community-based partnerships to improve patient safety in America and to involve consumers in the prevention of medical errors. This requires redesign of the health care together with the perspectives, experiences and participation of patients and family.</td>
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<td></td>
<td><a href="http://www.patientsafety.org/">http://www.patientsafety.org/</a></td>
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<td>Tool kit for patients and family with tips on what they must know and can do during the care process to prevent unsafe situations</td>
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<td>“Staying safe when you leave the hospital” (brochure, 5 pages):</td>
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<td>For patients and family with information on discharge from hospital:</td>
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<td></td>
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<td>- make an appointment with your main practitioner</td>
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<td>- ensure that you have a medication list</td>
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<td>- know what you can expect and can do</td>
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<td>- do not hesitate to ask questions and for information</td>
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<td>- ask for copies of your file, test results, etc., for at home</td>
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<td>“Talking to your doctor or nurse” (brochure 2 pages):</td>
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<td>For patients and family with tips for discussions with professionals:</td>
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<td>- write down your questions in advance</td>
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<td>- ensure that you know what medication you are using</td>
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<td>- take a notebook with you</td>
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<td>- talk about your main problem first</td>
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### Role of the patient in patient safety

**a necessity, not a desirability**

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<tr>
<th>24. <strong>“Your role in medicine safety”</strong></th>
<th>Pfizer (2002-2009)</th>
<th>Online information</th>
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<tr>
<td><strong>Tips for patients and family to prepare themselves emotionally for a discussion with a professional:</strong></td>
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<td>- if it is about your body, you are the expert</td>
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<td>- tell the doctor what is on your mind</td>
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<td>- ensure that your doctor takes your concerns seriously</td>
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<td>- trust your instinct, know what you are worth and speak</td>
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<td>- remind yourself what you must know and why</td>
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<td>- do not hesitate to ask: could there be anything else the matter? Express doubts about diagnosis</td>
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| **Tips for professionals on communicating with patients and family, including:** |
| - take your time |
| - explain things clearly |
| - ask patients and/or family members to repeat information and instructions |
| - ask for an interpreter if the patient and family do not speak the language |
| - pay attention to: what is the main problem? What can the patient do himself? Why is that important? |

This is online information for patients about their role in medication safety. Specifically mentioned is ‘partnering’ with care professionals: patients can help decide which medication is suitable for them and how they must take it.

You can help by:
- telling the doctor about your health and medication history (various tips are given for this)
- asking questions about your medication
- seeking advice from your pharmacist

### “The emotional side of healthcare: six tips for talking to your doctor” (brochure, 2 pages):

**Tips for patients and family to prepare themselves emotionally for a discussion with a professional:**

- say what medication you are using
- say who else is treating you
- write down the answers to your questions
- ask the professional to repeat things you have not understood
- repeat the instructions in your own words
- do not leave before all your questions have been answered
- make the next appointment
- speak up about any doubts or things that you need (such as transport)

### “Communicating with patients and families for smooth, safe hospital discharge – instructions for clinicians” (brochure, 2 pages):

**Information and tips for professionals on communicating with patients and family, including:**

- take your time
- explain things clearly
- ask patients and/or family members to repeat information and instructions
- ask for an interpreter if the patient and family do not speak the language
- pay attention to: what is the main problem? What can the patient do himself? Why is that important?

Appendix 3  Topic list interviews

1. What knowledge do you have about the role of the patient in patient safety?
   a. (Inter)National
   b. Care-wide

2. What knowledge do you have about the role of the patient in patient safety?
   a. Impacts
   b. Risks
   c. Influencing factors

3. What knowledge do you have about interventions/examples of the role of the patient in patient safety?
   a. Individual patient (e.g. the patient safety card)
   b. Patient collectives

4. What is your opinion (or your knowledge of the opinions of others) about the role of the patient in patient safety (in primary care process, but also in improvement initiatives)?
   a. Patient
   b. Care professionals

5. What gaps are there (for further research) in the role of the patient in patient safety?
   a. Better underpinning of tools
      i. Effectiveness
      ii. Desirability
      iii. Risks/dangers
   b. Development of more tools

6. What recommendations do you have about the role of the patient in patient safety?

7. What suggestions do you have with regard to this preliminary study?
   a. Tips for literature?
   b. Tips for web search?
   c. Tips for interviews with other organisations/people?
   d. Do you have best practices in this regard within your environment or outside?

8. Do you have any further comments/questions/tips?

9. Do you think there is anyone else we should approach on this subject?