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Involving burn survivors in agenda setting on burn research: An added value?

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ABSTRACT

Background and aim: The role of burn survivors in burn research is usually restricted to being objects of study and beneficiaries of research results, while decision-making on research is traditionally the domain of a small group of experts, mainly scientists. In this article we compare the research priorities of burn survivors and professionals and investigate to what extent it is possible to come to a joint research agenda.

Methodology: The project followed the Dialogue Model for research agenda setting. Initially burn survivors and professionals were consulted separately and group-specific lists of research priorities were established, using a literature survey, exploratory interviews ($n = 10$), focus groups ($n = 58$), a questionnaire ($n = 224$) and Delphi rounds ($n = 12$). Subsequently, in a dialogue meeting burn survivors and professionals presented and discussed their priorities, developed one integrated list, and prioritized the 15 most important topics on this list.

Results: Considerable overlap was observed between the research priorities of burn survivors and professionals, particularly with respect to biomedical and clinical research on wound healing and scar management. However, differences were also observed, e.g. treatment of itching and oedema on scars and donor places.

Conclusion: The model proved useful in eliciting research priorities from both professionals and burn survivors, and in stimulating a meaningful dialogue between these groups. The involvement of burn survivors identified burn research areas that are currently not the focus of research in The Netherlands.

1. Introduction

The role of burn survivors in burn research is usually restricted to being objects of study and beneficiaries of research results, while decision-making on what research is conducted is traditionally the domain of a small group of experts, mainly researchers. This 'task division' is certainly not only true for burn research, but also can be observed in health research in general. However, the past 10 years some change can be witnessed in this situation. For example, research funding agencies increasingly involve patients in their policy making [1–4].

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Patient participation in health research can in principle take place in all phases of the research process – from research programming and research design to research evaluation and dissemination of the research results – and can take many forms [5]. For example, patients can be members of a research programming committee, be involved in the review of research proposals, be consulted about their problems and needs, or assist in setting outcome measures for clinical trials. Patients may even fulfil the role of patient research partner; in that case they become part of a research team with professionally trained researchers. Furthermore, the level of control may differ. In some cases, patients only act as providers of information, or as advisors, while in other instances they co-decide with professionals or even may be the main drivers in the research process.

Three arguments are generally used to justify participation of patients in health research [5–8]. A first argument for involving patients relates to their role as stakeholder (as end users) of health research. As end users, patients would have the right to engage in discussions on research that is conducted for them (normative argument). A second argument for patient participation concerns increased levels of support for research. If patients are involved in deciding about what is researched, the legitimacy of the executed research is enhanced (instrumental argument). A third argument concerns the specific type of knowledge that patients obtain based on their daily experience with their disease; 'experiential knowledge'. It is argued that this knowledge can complement that of professionals in decision-making processes, including health research [9–11]. This is called a substantial argument. Patients can, thus, be considered both relevant stakeholders and potentially relevant (non-certified) experts within the field of health research. As such their involvement in decision-making on this research could increase both the political legitimacy as well as the quality of decisions.The normative and instrumental arguments are widely shared. However, the substantial argument is more controversial. Various stakeholders tend to be highly sceptical about the value of knowledge input of patients for health research. Caron-Flinterman et al. [12] found that many stakeholders feel that the health research system develops high quality medical innovations, improving the quality of life of patients, and that scientists know best what needs to be researched; they can identify the white spots in the scientific landscape and assess the feasibility of research. Involving patients may even jeopardize the effectiveness of the research system. After all, patients know little about scientific research and their experiential knowledge is highly subjective. Combined with the fear for delays and complication of decision-making processes, many stakeholders believe that the benefits of patient participation – if any – do not outweigh the disadvantages.

In this article we present and analyse the results of a research agenda-setting project of the Dutch Burns Foundation (NBS—'Nederlandse Brandwonden Stichting') in which, besides professionals in research, care and prevention, burn survivors were actively included in the process of data collection, analysis and decision-making. For research funding organizations, such as the Dutch Burns Foundation, not being directly related to clinical work, and having an interest in non-clinical topics (e.g. burn prevention) for research as well, it is very important to have a broad overview of the current research priorities. Preferably, priorities for burn prevention and burn care are laid down in one integrated research agenda that is broadly supported within the relevant professional and societal field. One integrated list is preferred over separate lists for burn survivors and professionals, since separate lists would imply that the Burns Foundation needs to weigh the priorities of burn survivors to that of professionals; in case of an integrated list the stakeholders indicate the weight of the different topics. The agenda should highlight important areas for research within the presently ongoing projects and grant submissions. In addition, it should identify presently under-represented areas for burn research that deserve an additional (financial) impulse. In order to establish a national agenda for burn research in the Netherlands, the Dutch Burns Foundation, in collaboration with researchers from the Athena Institute, VU University Amsterdam, set out an extensive, participatory trajectory entitled the BhURN project ('Brandwondenonderzoek heeft Uw Reactie Nodig'—burns research needs your response) in 2006, involving burn survivors and professionals in prevention, care and research.

We investigated to what extent there is a discrepancy between priorities of patients and professionals, how the different groups assess the value of each others priorities, and to what extent it is possible to come to a joint research agenda.

2. Methodology

The project followed the methodology of the Dialogue Model for patient participation in research agenda setting [5]. This model is grounded in the so-called responsive research methodology. In a responsive approach the issues of stakeholders are the starting point for a dialogue about the improvement of a certain practice. Stakeholders are people or organizations whose issues are at stake. Their involvement is based on the premise that each stakeholder has a specific perspective on the issue and that a dialogue among and between the stakeholder groups will result in a better informed, more sophisticated decision on the improvement of practice. The different stakeholders are actively involved in the process of design, data collection, analysis and dissemination. The responsive methodology was originally developed in the field of program evaluation, e.g. Refs. [13–15], and then translated to the field of health research [16–18].

The Dialogue Model has been validated in various case studies and comprises six underlying notions: active engagement of patients, conducive social conditions, respect for experiential knowledge, mutual learning, emergent and flexible design, and process facilitation [5]; Box 1). The activities are structured in roughly six phases: initiation and preparation, consultation, prioritization, integration, programming, and implementation. Essential for the successful execution of the model is a well-filled box of methods and tools for different functions, which can be adapted to the local context and dynamics. A combined use of qualitative and quantitative methods enables the collection and comparison of a large diversity of perspectives, and is therefore preferred.

The combination of consultation and collaboration seems a fruitful way of approaching patient participation [5]. Often, patient participation in agenda-setting concerns only consulting patients about their problems and needs

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Box 1. Underlying notions and phases of the Dialogue Model for research agenda setting

Underlying notions

Active engagement of stakeholders, including patients: the issues of different stakeholders are taken as a starting point for dialogues about research. Stakeholders will not only serve as information givers, but are actively involved in the process of designing, data gathering, interpretation and dissemination.

Good social conditions: realization of a genuine dialogue between stakeholders requires the creation of good social conditions, including openness, trust, respect and commitment of relevant stakeholders. These conditions are often not in place; both patients and professionals may have strong feelings and prejudices about each other and the desirability of patient participation, while the relationship is characterized by asymmetry in knowledge and power. Good social conditions thus need to be created actively and maintained throughout the agenda-setting process.

Respect for experiential knowledge: the perspective of patients is grounded in their daily experiences with their illness or disability. Research methods need to be used through which an understanding of the questions and concerns of patients are brought into the process.

Mutual learning: a genuine dialogue implies that participants learn in the process and may change their opinion through listening to each other and learning about each other's experiences. Mutual learning is fostered through face-to-face meetings. In such meetings participants ask questions, probe, argue and deliberate about their experiences and opinions.

Emergent and flexible design: since the issues of stakeholders cannot be known in advance the design cannot be pre-ordained. The design emerges gradually in conversation with all parties, although the basic ground pattern and separate phases of the methodology are preset. This means that input of one participant or stakeholder group forms the input for the other participant/stakeholder group, so that information gets redefined and deliberated during the process. It also means that research methods may vary between stakeholder groups in order to prevent exclusion and increase commitment.

Process facilitation: since the process should be fair and meaningful, the collaboration between parties is fostered by an independent process facilitator (no stake in the content of the outcome) who creates the conditions for successful participation and dialogue.

Phases

1. *Exploration*, in which the project team is established, a first assessment is made of the problems, ideas, opinions and wishes of patients and other stakeholders, and a start is made with creating conducive social conditions. Desk study and informal conversations/interviews with representatives of stakeholder groups provide exploratory information about the issues of different stakeholders.
2. *Consultation*, in which various stakeholder groups are consulted separately to develop a comprehensive list of issues that are relevant from the perspective of each stakeholder group. Asymmetries between stakeholders usually prevent a meaningful interaction right from the start. Stakeholders first need to go through a process of sensitization, and patients first need to feel empowered to realize a more equal interaction between patients and professionals. The consultation usually starts with the stakeholder group with the least influence – the patients – to give them a visible 'say' in the agenda-setting process. Focus groups are often highly appropriate to explore the breadth of issues, but other methods may be necessary, e.g. interviews, internet discussion, to enhance inclusion and commitment.
3. *Prioritization*, in which stakeholder groups value the different research topics identified during the previous phases and rank these in order of importance, resulting in stakeholder-specific research agendas. A questionnaire is often an appropriate method to involve large stakeholder groups, such as patients. When it concerns relatively small populations, a Delphi technique (repeated written responses) or focus group may be more appropriate.
4. *Integration,* in which participants exchange information, address conflicts and integrate the different research agendas through dialogue, resulting in one integral research agenda. A dialogue meeting is an appropriate method to realize integration through deliberation. However, communication between patients and professionals is complicated by diverging expectations and scopes, language barriers and the low status of experiential knowledge. To give each stakeholder group an equal 'say', dialogue meetings need to be carefully prepared and facilitated.
5. *Programming*, in which the integral research agenda is translated into a coherent program or action plan. Care needs to be taken that all stakeholder groups are also engaged in the translation of the integral research agenda into a research program.
6. *Implementation,* in which stakeholders implement the research program, monitor progress and evaluate results.

Source: Ref. [5].

through a questionnaire, interview or focus group, or including patients as members in a research programming committee. However in those cases the decision whether or not to use the knowledge input of patients is left to the experts, and in practice these knowledge inputs are hard to trace in the resulting research agendas [12]. Another option is to completely transfer power to patients. However, as Abma and Broerse [5] argued, it is difficult to see how the perspective of patients will be accepted and utilized by researchers, if control is simply shifted from researchers to patients. If patients and professionals work in collaboration, the voices and perspectives of all parties whose issues are at stake are included more effectively in the research process.

In the BhURN project the first four phases of the Dialogue Model for research agenda setting were conducted. Below we describe the activities that took place in these four phases.

2.1. *Phase 1. Preparation and exploration (January–March 2006)*

The aim of the first phase was to start with the creation of good social conditions and to obtain a rough overview of the stakeholder issues. The project team consisted of the research programme coordinator of the Dutch Burn Foundation, two internship students, and two staff members of the Athena Institute of the VU University Amsterdam (who gave advice on the design of the participation process and acted as facilitators for the various meetings organized).[1]

Relevant organizations in the field of burn research are, besides the NBS, the Dutch Association of Burn Survivors (VMB—'Vereniging Mensen met Brandwonden') and the Association of Dutch Burn Centres (ADBC) (see Box 2 for a brief description of these organizations). In a responsive methodology, primarily individuals (belonging to a certain stakeholder group) are consulted. However, the role of interest groups is not unimportant; interest groups may have accumulated knowledge that is relevant to gain an initial insight in the issues of the different stakeholder groups. In addition, such groups may be helpful in facilitating access to individuals of the stakeholder group whose interests they represent. In addition, their role in facilitating follow-up activities is important. Therefore, the project team will try to gain support and commitment of such interest groups for the process during the first phase.

One of the first activities of the team was to attend a meeting of the committee of the VMB—'Vereniging Mensen met Brandwonden') to present the project, to ask for feedback, and to assess their willingness to support the project. Subsequently, a desk study was conducted using scientific literature, policy documents (e.g. of the ADBC), as well as (autobiographic) articles and books of burn survivors. In addition, ten exploratory interviews were held with burn survivors (three), a clinical psychologist, the coordinator Department of Burn Care of the NBS, the director of research of the ADBC, a burn surgeon of one of the three burns centres in the Netherlands (also professor of burn care), a professor of applied psychology, a physical therapist, and the chair of the Scientific Advisory Board of the NBS (also professor of plastic surgery). These interviews were held (a) to obtain insight into topics that are relevant for the project, (b) to assess the level of support for the participatory process, and (c) to create commitment for the project. This phase ended with the development of the first newsletter – the BhURN letter – that was widely distributed among burn survivors and professionals to inform them about the activities and interim results of the project.

Box 2. Brief description of relevant organizations related to the BhURN project

Dutch Burns Foundation ('Nederlandse Brandwonden Stichting'—NBS)
The Dutch Burns Foundation aims to prevent burns and to keep the suffering as a result of burns to a minimum'. To fulfil this mission, the Burns Foundation is working towards three objectives:

- Improving the treatment, nursing, care for and assistance to persons with burns;
- enhancing the quality of life for persons with burns;
- burn prevention.

The NBS obtains its funds through private gifts. It is the main funder of burn research in The Netherlands.
Association of Dutch Burn Centres (ADBC)
Aim of the association is to stimulate cooperation between the three Dutch Burn Centres (Beverwijk, Groningen en Rotterdam), by stimulating research, education and training. This makes the VSBN a centre of excellence in the field of burn care and burn research. The ADBC was established in 2004 as a continuation of the research department of the Dutch Burns Foundation. Research of the ADBC is focused on preclinical, clinical, psycho-social and epidemiological research.
Dutch Association of Burn Survivors ('Vereniging Mensen met Brandwonden'—VMB).
The Dutch Association of Burn Survivors is founded by burn survivors and people closely related to burn survivors. The key aim of the Association is to improve the quality of life of burn surivivors, so that they can resume their 'normal' lives as much as possible. The association was established in 1977 and now has 490 members. Members are burn survivors, parents of children with burns, partners, brothers, sisters and others close to a burn survivor. The association has the following focal points:

- Improving provision of information and advice to burn survivors and others;
- enhancing contact between burn survivors, their parents/care takers, partners and family members;
- advocacy with respect to quality of life of burn survivors.

2.2. *Phase 2. In-depth study (April–June 2006)*

In this phase the research agendas of the participating stakeholder groups were identified. The groups were consulted separately, because the asymmetry between them usually prevents a meaningful interaction right from the start. It is highly likely that professionals will dominate discussions and may even overrule burn survivors, since burn survivors have not yet had the opportunity to form an own opinion on health research. Furthermore, professionals and burn survivors use a different 'language'. In general, patients first need to be empowered, while professionals need to be sensitized for experiential knowledge, before a dialogue can take place in a

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[1] When the students finished their internship, another NBS staff member was added to the team. All authors were part of the project team.

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meaningful way. In the BhURN project, two parallel trajectories – one focussing on burn survivors and the other focussing on professionals – were therefore conducted.

Burn survivors: the project team used the focus group method to make an inventory of problems and questions of burn survivors. A convenience sample was used; invitations were broadly sent out and all those interested to participate in the focus groups were included. The VMB made an announcement in their journal and the NBS invited members by letter. In addition, announcements were put on the websites of the NBS and VMB. Both burn survivors as well as parents of burn survivors participated in the focus groups.

During the five focus groups ($n = 37$), first the problems and questions of burn survivors were identified, discussed and clustered in themes. Burn survivors were initially asked to mention three problems. These problems were all listed and discussed. Then participants were asked to mention additional problems that were not yet listed. The issues were then placed on a 'time line' (before incident → first aid → intensive care → hospital → rehabilitation → afterwards) for further analysis and discussion, and to further probe whether there were still additional problems that had been left out. In the last exercise, the participants valued the various issues by indicating the three topics they thought most important, and discussed the overall result. Since participants may experience coping problems, a trained coach from the VMB was present during each focus group to provide assistance to participants, if necessary. A report was sent to the participants for member check.

After the focus groups we investigated whether participants covered a sufficiently broad range of characteristics with respect to differences in burn severity, type of burns, time since burn accident, geographical location, age and gender. Children and adolescents did not directly participate in the focus groups. To obtain some insight in the specific problems of children and adolescents, parents of burn survivors participated in the focus groups. In addition, two interviews were held with nurses working with children at a burns centre. Children were not interviewed, because this required approval of a medical ethical committee which would take a couple of months and did not fit the time schedule of the project.

The results of the meetings were analysed and visualized in an argumentation tree. In an argumentation tree the underlying causes (e.g. the burn accident) are listed below and towards the top the effects are listed (e.g. a reduced quality of life). In two feedback meetings the results were presented and discussed with in total 16 participants of the focus groups.

Professionals (prevention, health care and research): the inventory of issues of professionals started during the previous phase with an analysis of the policy document produced by the ADBC in 2004. This policy document described the priorities in preclinical, clinical, psychological and epidemiological research from the perspective of the professionals in the burn centres. This was the only document reflecting the research priorities of professionals in The Netherlands, since the NBS had not previously set priorities with professionals. In addition, various programmes of recent scientific conferences, such a those of the European and American Burn Association, were studied.

In order to get a broader view, during this second phase the project team organized three thematic focus groups on rehabilitation, basic research, and prevention, particularly also including professionals outside the Dutch burn centres, such as basic researchers in academic settings and experts in burn prevention and rehabilitation. In the focus groups relevant research topics were identified. Participants were first asked to mention three important research topics; after listing these topics, participants were asked to name additional topics. Subsequently topics were clustered in themes. Then the research coordinator of NBS gave a brief overview of an inventory study on current research concerning the theme of the meeting. This was compared to the topics identified by the participants. If participants felt topics were missing on 'their' list, these were added. In the last exercise the participants valued the different topics, selecting their top three, and discussed the results. Workshop reports were prepared and sent to participants for member check.

In May 2006, the second BhURN letter was published.

2.3. *Phase 3. Prioritization (May–August 2006)*

The main objective of this phase was the establishment of a research priority list from the perspective of each stakeholder group. Each stakeholder group prioritized research topics from an extensive list that had been produced during the previous phase.

Burn survivors: prioritization (voting) took place by means of a questionnaire. The 60 problems and questions derived from the literature study, interviews and focus groups with burn survivors were translated to 60 topics for research and clustered in 10 research themes (see Table 1). The themes and topics formed the backbone of a questionnaire in which burn survivors were asked to prioritize themes and topics within themes. The questionnaire was pilot tested during the two feedback meetings with burn survivors (who had participated in the focus groups) and subsequently amended. The feedback not only concerned whether the questionnaire was doable, but also whether the participants felt the results from the focus groups were well translated into the questionnaire.

The questionnaire consisted of three parts. The first part concerned relevant characteristics of the respondent, who was either a burn survivor or a direct relative of a burn survivor. In the second part respondents were asked to name their top three research topics (out of the six topics) within each of the themes by giving respectively three, two and one point(s) to their number one, two and three most important research topics. Respondents were also requested to select their top 4 themes (out of the 10 themes). The third part of the questionnaire concerned a number of evaluative questions and invited the respondents to make remarks.

The VMB distributed questionnaires to all their members, while the NBS distributed questionnaires to an a-select sample of their members; in total they distributed 801 questionnaires. Two weeks after distribution a reminder was sent. In addition, questionnaires were distributed via a rehabilitation centre (59), the Foundation 'Child and Burns' (52), and the holiday camps for adolescents with burns (46) to reach people with burns who are probably not a member of the VMB or NBS. This

Table 1 – Final score of research themes and topics of burn survivors—those in bold are part of the top 15.

Theme burns and scar treatment (22.4%)	
Children who must undergo recurrent operations due to growth	**(31%)**
Physical stress due to recurrent operations	**(23%)**
Infection or inflammation of burn wounds in the hospital	**(13%)**
Negative impact of medication, such as anesthesia and pain medication	(12%)
Functioning, users convenience and comfort of pressure clothes	(11%)
Amputation of limbs and the impact of it	(10%)
Theme skin and burn scars (18.3%)	
Problematic scar formation (e.g. hypertrophic scar formation, insensibility or discoloration of the skin	**(25%)**
Itching and oedema on scars and donor places	**(20%)**
Reduced mobility due to scars	**(18%)**
Pain due to the burn wounds (scars) (not the pain during bandage changes)	(15%)
Vulnerability of the skin after operation and returning sores	(12%)
Influence of growing older on scars	(11%)
Theme burn care in hospitals (14.3%)	
Quality of the burn care in regional hospitals	**(28%)**
Bandage changes in hospital (e.g. pain or wet bandage)	**(17%)**
Knowledge of doctors in the hospital about treatment possibilities	(16%)
Treatment and medication in the hospital	(15%)
Relation between doctors and burn survivors	(13%)
Organization and coordination of the Dutch burn care	(12%)
Theme psycho-social problems of burn survivors (13.3%)	
Emotional complaints, such as fear, depression, feelings of guilt, anger and coping	**(24%)**
Mental problems of children and adolescents with burns (e.g. fear, guilt or anger)	**(22%)**
Shame and changed self-image compared to before a burn accident	(19%)
Hospital trauma of children with burns	(13%)
Emotional stress due to recurrent operations	(12%)
Memory defect, concentration problems and sleep disorders	(10%)
Theme care and support after hospitalization (11.5%)	
Accessibility of mental and social care after the 1st hospital period	**(26%)**
Quality of psycho-social outpatient care	**(24%)**
Availability and quality of the physical readjustment after the 1st hospital period	(18%)
Compensation of care costs by insurers, accompaniment and legal advice	(13%)
Accessibility and quality of rehabilitation care, e.g. fysio therapy and ergo therapy	(10%)
Indemnity insurance procedures, supporting and legal advice thereby	(9%)
Theme psycho-social problems of people in the surroundings (5.4%)	
Impact of the burn on family life	**(39%)**
Mental problems of parents of children with burns (e.g. guilt feelings)	(21%)
Psycho-social problems of partners or friends of burn survivors	(11%)
Well-being of brothers and/or sisters of burn survivors	(9%)
Responses of ignorance towards parents of children with burns	(9%)
Psycho-social problems of children of burn survivors	(9%)
Theme participation in society (4.6%)	
Social problems of children and adolescents with burns	**(27%)**
Unpleasant responses from the surroundings towards burn survivors	(19%)
Work, employer and (partial) incapacity for work after the burn accident	(19%)
Social contacts with people who have no burns	(14%)
Intimate relations in the present and the future	(14%)
Taboo on suicidal attempts in relation to burns	(7%)
Theme first aid (3.6%)	
Expertise in regional hospitals (regarding First aid of burns)	**(29%)**
Expertise of general practitioner (regarding First aid of burns)	(17%)
Relief of victims and their fellows at the first aid of the hospital	(17%)
First aid by spectators	(13%)
Expertise of the ambulance staff	(13%)
Organization and coordination of the First aid of the Dutch burn care	(12%)
Theme provision of information (3.5%)	
Provision of information after release from the hospital	(22%)
Information to prevent burns and limit the severity of burns	(22%)
Information during the 1st hospitalization	(19%)
Information concerning possible follow-up treatments, for example laser or camouflage therapy	(16%)
Information concerning wound and scar care at home	(15%)
Provision of information and communication concerning scientific research in which patients can take part	(7%)

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Table 1 (*Continued*)

Theme remaining physical problems (3.1%)	
Problems with the nervous system or organs, such as heart and lungs	(25%)
Restrictions in physical activities by reduced condition	(24%)
Infection or inflammation of burns at home	(17%)
Changed metabolism and dietary pattern after the burn accident	(13%)
Oedema (swelling of body parts by fluid accumulation)	(11%)
Extreme dehydration and feeling of sickness during the 1st days after hospitalization	(11%)

meant that a 'convenience sample' was used. Beforehand the project team decided that the priority list of burn survivors would consist of 15 topics; this was 25% of the total number of topics and considered a manageable amount as input in the next phase. By using a weighing formula, the project team determined how many research topics of each theme were included in the priority list. The number of points given to theme X was divided by the total number of points of all themes, multiplied by 15; this gives the number of topics of theme X that will be included in the research agenda of burn survivors.

Professionals: after the focus groups with professionals the project team clustered the selected research topics according to type of research. This resulted in three lists: (pre-)clinical research, psycho-social and rehabilitation research and prevention (epidemiological) research. The first two lists contained many topics. These lists were prioritized using various written and oral rounds (Delphi method) among a larger group of professionals than those involved in the focus group. This resulted in a research agenda on (pre-)clinical research consisting of eleven research topics and a research agenda on psycho-social and rehabilitation research comprising ten research topics. The focus group on prevention had yielded a limited list of five research topics. This list was not further prioritized.

The project team integrated the various argumentation trees that were produced after each focus group and analysed the different lists. In July, the third BhURN letter was published.

2.4. *Phase 4. Integration (June 2006–February 2007)*

The aim of this phase was to integrate and further prioritize the priorities of the different stakeholder groups via dialogue and voting. To this end, a dialogue meeting was organized. From the list of people that had participated in previous phases of the project, 36 participants (18 burn survivors and 18 professionals) were invited on the basis of their background, 'helicopter view', willingness to enter into a dialogue and their availability. The project team organized a preparatory meeting for invited burn survivors one week prior to the dialogue. During this preparatory meeting, which was attended by 8 participants, the results of the questionnaire were presented, discussed and related to the discussions during the focus groups. In addition, more background was provided on the nature, setup and aim of the dialogue meeting.

The dialogue meeting was attended by 14 burn survivors and 15 professionals (scientists from various disciplines, (plastic) surgeons, psychologists, rehabilitation practitioners and prevention experts). During the first part of the meeting an overview was provided of the interim results of the project. Subsequently, the participants were divided into three heterogeneous working groups. In each group, the participants discussed the four different priority lists, particularly focussing on observed similarities and differences. Apart from a substantive, analytical goal, the discussion was meant to induce reflexive learning; it was envisaged that participants from various stakeholder groups would better understand why certain research topics featured on a priority list. This might lead to eye openers and perhaps amendment of opinions. Next the working groups were requested to integrate the four priority lists into one list with thematized research topics. The results of the working groups were presented and discussed in a plenary session and agreement was reached on one integral priority list. In a last exercise the integral list was further prioritized. The participants were requested to list the 7 themes in order of importance (number 1 getting nine points, number 2 seven points, number 3 five points, number 4 four points and so on) and to make a top ten of research topics (number 1 getting twelve points, number 2 ten points, number 3 eight points, number 4 seven points and so on). The filled in lists were processed, and the results were presented and discussed during the closing session of the meeting. A report of the dialogue meeting was sent to participants for member check.

As a final activity within the BhURN project a final report was prepared [19].

During the research project, various measures were taken to enhance the quality of the research. The following quality criteria have been formulated by Guba and Lincoln [13] for research based on the responsive research methodology: credibility, fairness, and satisfaction.

Credibility is enhanced through member check and triangulation.[2] In this project member check was realized through written reports of interviews, focus groups and the dialogue meeting, distribution of a newsletter, as well as several feedback meetings. Triangulation was realized by using various research methods—document analysis, interviews, focus groups, questionnaire, Delphi rounds and dialogue meeting. Also various data sources were used by using both written and oral sources and by striving for the inclusion of a large diversity of respondents and participants.

Fairness of a dialogical process is enhanced when relevant stakeholders are enabled to participate in the process in an open and respectful way and their voice is visibly included. This implies that measures need to be taken to counteract

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[2] Triangulation is achieved when two or more research methods, data sources or researchers are used. When the same results are obtained when using different methods, data sources or researchers the credibility of the results is enhanced.

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asymmetrical power relations between the different stakeholders. When a dialogical process includes patients as well as professionals asymmetrical power relations clearly exist. 'True' knowledge is often regarded as data generated through robust scientific research. Indigenous, unsystematized or unprofessional knowledge, such as the experiential knowledge of patients, are judged to be much lower in the knowledge hierarchy, not only by professionals but also by patients [7]. Patients often lack self-confidence and are uncertain about the relevance of their experiential knowledge particularly in relation to scientific research—a topic they often know little about and have rarely formed an opinion on.

In the project, care was taken to prevent exclusion and bias of stakeholder subgroups within the process. Together with the VMB we identified certain characteristics of burn survivors that could influence their problems and research preferences, such as severity of burns, time passed since burn accident, age and gender, and we carefully monitored inclusion of the various subgroups along the way. Also with respect to professionals a list was made of professions and academic backgrounds that were relevant in the process.

Various measures were taken in the project to redress the power balance between burn survivors and professionals. Firstly, we consulted burn survivors through a more elaborate process to enable them to form an opinion on preferred research topics. By also engaging a broader group of burn survivors through a questionnaire the inter-subjectivity was enhanced, which made the priorities of burn survivors more legitimate from the perspective of professionals. Secondly, a feedback and preparation meeting was organized for burn survivors prior to the dialogue meeting to acquaint the invited burn survivors with the top 15 of priority research topics they would be discussing on behalf of the group of burn survivors and also to provide more background on the nature of the dialogue meeting. Thirdly, as of the beginning of the process professionals were asked about their opinion on patient participation in research and potential benefits were specifically put to their attention. Fourthly, during the dialogue meeting results of the previous phases were presented in such a way that overlaps in priorities were clearly visualized and the additional contribution of burn survivors was highlighted. Next, equal numbers of burn survivors and professionals were invited. Furthermore, one of the criteria to invite professionals was their openness to patient participation and their willingness to engage into a dialogue (otherwise they are not open to the inputs of patients and only tend to persuade patients to take their point of view). Finally, professional facilitators guided discussions and were specifically attentive to the fact that burn survivors were included in the discussions and were not overruled or in any other way dominated by professionals.

In a responsive research approach it is important that participants are *satisfied* with both the outcome and the way the outcome has been reached. Do participants themselves feel that they have been sufficiently engaged in the process? Was the process transparent and were methods used clear? Is the result more broadly supported by relevant stakeholders who were not actively involved in the process? Therefore, we regularly asked participants after the focus groups, at the end of the questionnaire, and after the dialogue meeting to what extent they were satisfied with the process and the (intermediary) outcome.

3. Results

The results of the BhURN project are presented in this section in three clusters. Firstly the findings with respect to the in-depth and prioritization phases with burn survivors are presented, followed by the results from these phases with professionals in prevention, care and research. Finally a description of the results of the integration phase is provided.

3.1. *Burn survivors*

In total, 37 participants attended the five focus groups on three locations in the country (6–11 participants per focus group). Twenty-six people were burn survivors, 10 were parents of children with burns and 1 participant was the partner of a burn survivor. The participants differed in the way the burns were acquired, the severity of the burn wounds, the time since the burn accident, geographical location, age and gender.

The results of the five separate focus groups were quite similar, and are therefore discussed collectively. The discussions with respect to the problems primarily focussed on aftercare (care after hospitalization) and the general organization of burn care. However, many other issues were also raised, which resulted in a broad range of problems and questions. These problems and their underlying causes were visualized in an argumentation tree (see Fig. 1). The themes that were considered most important were lack of psycho-social and physical aftercare, psycho-social problems of burn survivors, poor information supply, unprofessional first aid and diagnosis, and impact of burns on close relationships.

During the prioritization phase a questionnaire was sent to 958 burn survivors. In total, 224 burn survivors returned a completely filled in questionnaire (response of about 25%). Of the respondents 63% was female and 64% was between 31 and 60 years old. Almost half of the respondents were initially admitted to a regional hospital and 25% was directly sent to one of the three burn centres in the Netherlands. The final results of the questionnaire are listed in Table 1. The theme 'burn and scar treatment' obtained almost a quarter of the votes. Other themes that obtained between 18.3 and 11.5% of the votes were skin and scars, burn care in hospitals, psycho-social problems of burn survivors and care after hospitalization. The 15 research topics included in the priority list of burn survivors are printed in bold in Table 1.

3.2. *Professionals in prevention, care and research*

During the focus group on rehabilitation, which was attended by seven professionals (see Table 2), the main problem identified was the lack of scientific grounding of rehabilitation practice and policies in burn care. There is a lack of uniform protocol and the protocols used are usually not based on evidence-based medicine. In the Netherlands, the infrastructure for the design and execution of rehabilitation research for burns is poor and, due to a lack of a uniform registration system (at least in 2006), there is insufficient insight in the most pressing problems with

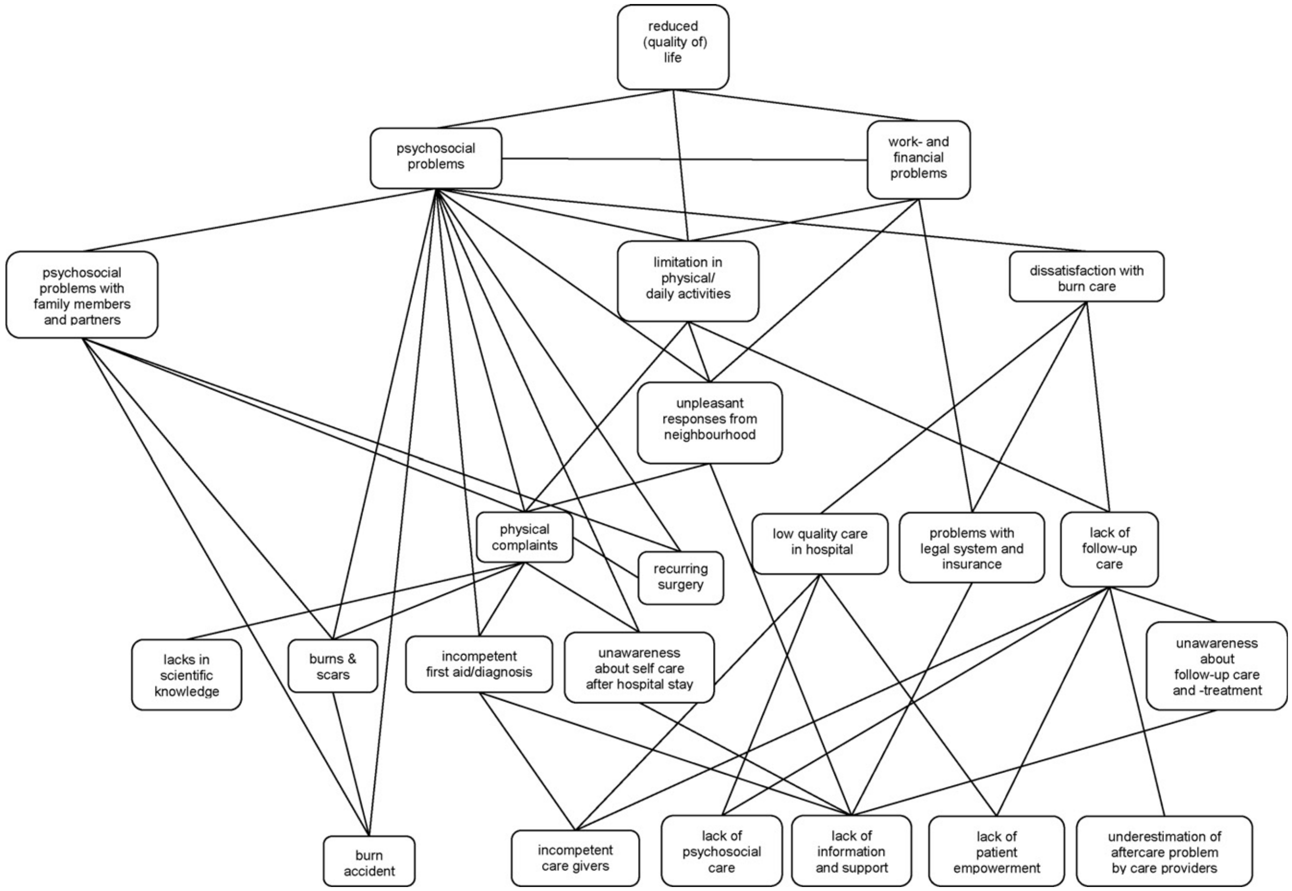

Fig. 1 – Simplified argumentation tree of burn survivors.

respect to rehabilitation research. In addition, there is a need for the development and verification of measurement instruments so as to determine the effectiveness of different treatments.

The 6 participants of the focus group on basic research (see Table 2) considered control of infection and inflammation, and tissue regeneration the most important themes. Sorting out the mechanisms that play a role in wound healing and scar formation was mentioned as a very relevant research topic, and attention was specifically asked for innovative research on this topic. The development of skin substitutes for optimal wound healing (e.g. via tissue engineering) and of strategies to control infection and inflammation were other relevant research topics.

The 6 participants of the focus group on primary prevention (see Table 2) focussed specifically on the lack of (inter)national data concerning the determinants of burn incidents, as well as on the effectiveness of intervention strategies. This lack is seriously constraining epidemiological research on determinants for effective prevention of burn accidents. Instead of mentioning separate priority topics, the participants came up with a five-step approach comprising five essential, and interdependent topics for prevention research, moving from epidemiological data on burns in the Netherlands, to the development of a (political) lobby to implement effective prevention strategies (see Table 3).

Together with the topics mentioned in the policy document of the ADBC followed by several oral and written Delphi rounds, this resulted in three priority lists on preclinical and clinical research (11 topics), psycho-social aftercare and rehabilitation research (10 topics), and prevention (5 topics) (see Table 3).

Table 2 – List of professional/disciplinary background of participants in the focus groups on rehabilitation, basic research and primary prevention.

Rehabilitation	Basic research	Primary prevention
Rehabilitation science	Plastic and reconstructive surgery	Psychology
Rehabilitation medicine	Pharmacology and toxicology	Consumer Safety
Physical therapy	Skin biology	Public Health
Occupational therapy	Experimental dermatology	Health Promotion
Clinical research	Pathology	Prevention
	Dermatology	

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Table 3 – Priority lists of professionals on preclinical and clinical research, psycho-social aftercare and rehabilitation research, and prevention.

Preclinical and clinical research	Psycho-social aftercare and rehabilitation research	Prevention
Sorting out mechanisms in wound healing and scar formation	Tracing risk factors for development of long-term adaptation problems (e.g. PTSS)	Mapping epidemiological data on burn accidents in the Netherlands
Attention for innovative, pioneering research for improved wound healing	Impact of treatment on development of (PTSS[a]) problems	Mapping (international) state-of-the-art and best practices on prevention
Development of artificial dermis for wound healing	Development and nature of behavioural problems in children	Determine and analyse determinants of burn accidents
Development of strategies to intervene in process of infection and inflammation	Aspects of labour reintegration and lesion damage procedures	Development and evaluation of intervention strategies
Development and testing of measurement instruments for wound cicatrisation (1st)	Impact of burn accident on relatives	Development of (political) lobby for prevention of burn accidents
Development and testing of treatment protocols for wound healing	Psycho-social aspects of having (burn) scars	
Development and testing of protocols for first aid	Influence of stretching on burn scars and development of contractures	
Development and testing of protocols for intensive care	Rehabilitation strategies to influence scar formation	
Development and testing of protocols for specific patient groups (e.g. children, elderly)	Development and testing of protocols for rehabilitation	
Data registration concerning context, details and outcomes of treatment of individual patients in standardized way	Development and testing of measurement instruments for rehabilitation	
More attention for complementary treatment methods and their effectiveness		

[a] PTSS = post-traumatic stress syndrome.

3.3. *Integration through dialogue*

During the integration phase a dialogue meeting was organized. After a presentation of the results thus far, the participants were divided in three heterogeneous groups. The groups discussed similarities and differences between the priority lists of professionals and the list of burn survivors and to cluster the topics into themes. Some of the professionals expressed their content with having the opportunity to discuss priorities in research with professionals of different disciplines and with burn survivors. There was general surprise the overlap between the lists of professionals and that of burn survivors. The unique points on each list were explained and discussed.

At the end of the session the groups integrated the four lists into one list. In a plenary session the 41 topics were clustered in 7 themes. This took quite some time because the three groups had come up with quite different integrated lists, using a different rationale for clustering.

During the second part of the meeting the participants prioritized the 7 themes and selected their top 10 of priority topics. The results are presented in Table 4. About 60% of the participants put the theme tissue regeneration on the first or second place (about 40% put this theme at top position). Topics of all four initial agendas were included in the top 15 of research topics. It is interesting to note that among the 15 topics that were given high priority there were no topics related to the theme on treatment protocols. The highest topic within this theme – 'development and testing of treatment protocol(s) for wound healing' – ended at number 19.

Since participants were asked to fill in whether they belonged to the group of burn survivors or professionals, we could analyse the difference in voting behaviour between the two groups. When examining at the ranking of the themes there is much overlap particularly concerning the top 3 of themes, although the order differed. Professionals had the following top three (in order of decreasing importance): tissue regeneration, scar management and psycho-social problems. Burn survivors mentioned the same themes in their top three but in a different order: psycho-social problems, tissue regeneration and scar management. A significant difference is observed at the bottom of the list of themes; while professionals considered the theme organization and quality of care of lowest priority, burn survivors put this theme as number four.

In Fig. 2, we show how the group of burn survivors and professionals voted with respect to the top 15 of research topics. It can be seen that participants of the dialogue meeting partly prioritized 'own' topics, but certainly not exclusively. For example, some professionals prioritized the topic 'itching and oedema on scars and donor places' that was put forward only by burn survivors. Similarly, burn survivors also prioritized the topics 'mapping epidemiological data on burn accidents' and 'determine and analyse determinants of burn accidents' that were exclusively brought up by professionals. In that respect, the integration phase was effective; participants tried to explain to each other why they had put certain topics on their research agenda, and were willing to adjust their opinion in the light of arguments provided by other groups.

However, it should be noted that the general voting behaviour of burn survivors was substantially different from that of professionals. Within the top 4 of both groups there were no overlapping topics. Burn survivors considered 'itching

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Table 4 – Scores (in points) of research themes and research topics given by participants of the dialogue meeting. Topics belonging to the top 15 are given in 'bold' and topics from the original list of burn survivors are presented in 'italic'.

I	Tissue regeneration—160 points	
a	**Sorting out mechanisms in wound healing and scar formation**	**117**
b	**Attention for innovative, pioneering research for improved wound healing**	**69**
c	**Development of artificial dermis for wound healing**	**74**
d	**Development of strategies to intervene in process of infection and inflammation**	**66**
e	**Infection or inflammation of burn wounds in the hospital**	**46**
f	**Itching and oedema on scars and donor places**	**94**
g	Development and testing of measurement instruments for wound cicatrisation (1st)	19
II	Scar management—151 points	
a	*Children who must undergo recurrent operations due to their grow*	11
b	*Physical stress due to recurrent operations*	25
c	**Problematic scar formation (e.g. hypertrophic scar formation, insensibility or discoloration of the skin**	**72**
d	**Influence of stretching on burn scars and development of contractures**	**90**
e	**Rehabilitation strategies to influence scar formation**	**63**
f	*Limited stretching due to scars*	33
g	Development and testing of measurement instruments for rehabilitation	18
III	Treatment protocols—106 points	
a	Development and testing of treatment protocols for wound healing	35
b	*Bandage changes in hospital (e.g. pain or wet bandage)*	27
c	Development and testing of protocols for first aid	14
d	Development and testing of protocols for intensive care	19
e	Development and testing of protocols for specific patient groups (e.g. children, elderly)	11
f	Development and testing of protocols for rehabilitation	22
g	More attention for complementary treatment methods and their effectiveness	22
IV	Psycho-social problems—155 points	
a	Development and nature of behaviour problems in children	8
b	*Mental problems of children and adolescents with burns (e.g. fear, guilt or anger)*	**24**
c	Impact of burn accident on relatives	35
d	Tracing risk factors for development of long-term adaptation problems (e.g. PTS)	44
e	Impact of treatment on development of (PTSS*) problems	13
f	**Psycho-social aspects of having (burn) scars**	**57**
g	*Emotional complaints, such as fear, depression, feelings of guilt, anger and coping*	26
h	**Quality of psycho- social follow-up care**	**71**
i	**Impact of the burn accident on family life**	**51**
j	*Social problems of children and adolescents with burns*	11
k	Aspects of labour reintegration and lesion damage procedures	24
V	Data mapping and management—113 points	
a	**Data registration concerning context, details and outcomes of treatment of individual patients in standardized way**	**59**
b	**Mapping epidemiological data on burn accidents in the Netherlands**	**70**
VI	Organization and quality of burn care—81 points	
a	*Accessibility of the mental and social follow-up care after the 1st hospital period*	22
b	*Quality of the burn care in regional hospitals*	19
c	*Expertise in regional hospitals (regarding First aid at burns)*	14
VII	Prevention—75 points	
a	**Determine and analyse determinants of burn accidents**	**47**
b	Development of (political) lobby for prevention of burn accidents	6
c	Mapping (international) state-of-the-art and best practices on prevention	41
d	Development and evaluation of intervention strategies	15

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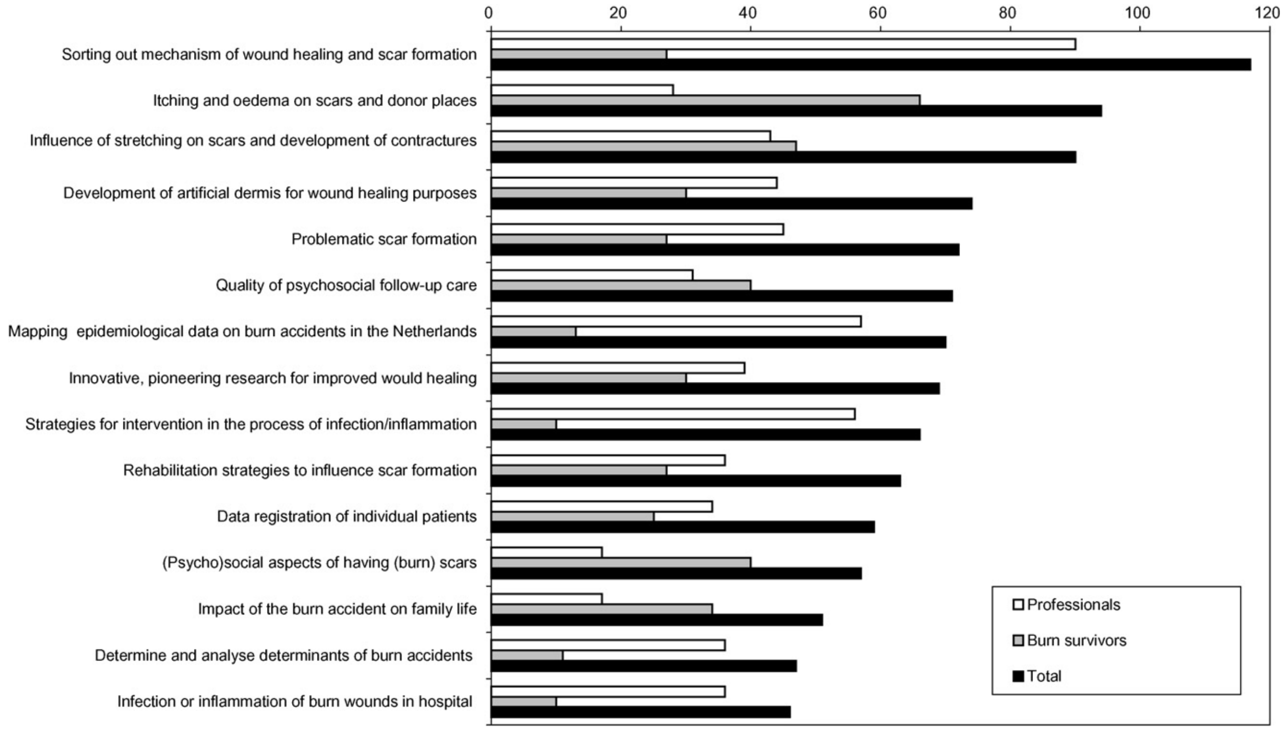

Fig. 2 – Fifteen most highly prioritized research topics with total number of points given and split into points given by professionals and by burn survivors.

and oedema on scars and donor places', 'influence of stretch on burn scars and development of contractures', 'quality of psycho-social aftercare', and '(psycho-)social aspect of having scars' most important research topics. The first issues concerning the theme of tissue regeneration are found at numbers 6, 7 and 8. Professionals, on the other hand, prioritized the topics 'sorting out mechanisms involved in wound healing and scar development', 'mapping epidemiological data concerning burn accidents', 'development of strategies for intervening in the process of infection/inflammation', and 'problematic scar formation' highest. The high position of the topic concerning epidemiological data is noteworthy since the theme 'registration and data management' scored quite low among professionals. Furthermore, it is interesting to note that professionals prioritized psychosocial problems as number 13.

4. Discussion

In this section we discuss the quality of the research with respect to the criteria credibility, fairness and satisfaction.

With respect to credibility some limitations were observed. Firstly, not all research methods yielded similar results. This was particularly observed with respect to the consultation of burn survivors by means of focus groups and questionnaire. During the focus groups issues (problems and questions) concerning tissue regeneration and scar management were hardly mentioned, while they were prioritized highly in the questionnaire as research topics. The differences in results were discussed during the feedback meeting with burn survivors that took place after the questionnaire. Various explanations were suggested. One explanation was that a larger and slightly different group of burn survivors participated in the questionnaire compared to the focus groups. Focus groups typically attract people that are quite 'active' at least with respect to the topic of the group discussion. However, analysis of the voting behaviour of focus groups participants who also participated in the questionnaire indicated that their voting was not substantially different from that of respondents who did not participate in the focus groups. A more plausible explanation – also mentioned by the participants at the feedback meeting – is the difference in focus. The focus groups concerned the *problem* issues, while the questionnaire concerned *research* topics. In case of the questionnaire respondents probably also take into consideration whether research might effectively solve a certain problem.

With respect to fairness the following limitations were observed. Firstly, certain groups of burn survivors were excluded—children and adolescents, and recent burn survivors who are still hospitalized. In addition, in relation to the questionnaire there was quite some self-exclusion among burn survivors given the response rate of about 25%. Whether or not this has influenced the outcome is unknown, since we have no insight into the preferences of non-respondents. With respect to professionals we expect that some bias has occurred because particularly health professionals and researchers from the network of the Dutch Burns Foundation were invited. This bias was partly redressed when during the third phase a broader group of professionals was consulted. Groups of health professionals not included were (research) nurses and

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anaesthesiologists. This is an omission in the design of the agenda-setting process.

With respect to satisfaction of the participants concerning process and outcome, we conclude that there was overall a broad satisfaction. In relation to the process, the focus groups of both burn survivors and professionals were quite satisfactory to the participants and the project team. In a short period of time in-depth discussion among participants took place and much data were obtained. The Delphi rounds with professionals were, however, less positively evaluated at least by the project team. The Delphi method proved time consuming, because reaching consensus was quite an extensive process. The lack of interaction between participants made the weighing of different individual opinions more difficult and made recurrent rounds necessary. Lack of response of some participants made it hard to assess the extent to which consensus was actually reached on the priority lists.

During the dialogue meeting, the project team had decided to include the phase of individual prioritization at the end of the meeting. Although this gave participants the opportunity to become informed about, and to reflect on, the final result already during the meeting, it also necessitated processing and analysis of results right on the spot in a short time period. Apart from causing time constraints on the part of the project team, some participants indicated that the process was hard to follow.

With respects to the overall process, various patients indicated that they felt taken seriously and found it interesting to discuss research priorities.

Patients were in general quite satisfied with the outcome of the process, although they regularly expressed that their final judgement very much depended on the extent to which their priorities would be translated into actual research projects and tangible results. Most professionals were also content with the outcome. Some had feared beforehand that burn survivors would come up with priorities unsuitable for research, such as ‘‘more cars for the fire brigade’’. They were pleasantly surprised to find out that burn survivors to some extent prioritized the same research topics as professionals.

5. Conclusions

It can be concluded that the Dialogue Model for research agenda setting proved quite useful in eliciting research priorities from both burn survivors and professionals in prevention, care and research. It was also effective in stimulating a meaningful dialogue between these groups; burn survivors and professionals listened to one-another and learned from each other.

However, some points for improvement were identified as well. Next time we would not include the Delphi method to reach consensus among professionals; a consensus meeting might be more appropriate. It is less time consuming and does not require the project team to make in-between analyses by weighing the different contributions. In addition, during the dialogue meeting the integration step –coming to one integral list with 41 research topics clustered in seven themes– was not clear to all participants. More time should have been taken for this step to make sure everybody could join in and make it a truly joint product. This implies that it is better not to include the final priority setting step in the same meeting (making the meeting longer is no option given the fact that it was already quite tiring particularly for many burn survivors). Furthermore, it would be interesting to investigate to what extent bias has occurred in the priority lists due to the exclusion of some groups in the process –children, adolescents, hospitalized burn survivors, nurses and anaesthesiologists. It could very well be that they have a perspective that is different from the groups whose voices were included.

With respect to the research priorities, we conclude that there is considerable overlap between the research priorities of burn survivors and professionals, particularly with respect to the research themes wound healing and scar management. However, differences are also observed. Burn survivors put more emphasis on psycho-social aftercare and on the organization and quality of care as compared to professionals. Some themes were exclusively brought up by professionals, such as treatment protocols and prevention. Also during the dialogue meeting these themes did not raise enthusiasm among burn survivors. Prevention even turned out to be a sensitive issue to many burn survivors; something they did not like to think about, because it brought back painful memories.

On the other hand, some research topics were exclusively brought in by burn survivors, such as itching and oedema on scars and donor places, bandage changes in the hospital and topics related to organization and quality of burn care. The research topic of itching and oedema even ended up second in the integral top 15, also being prioritized by professionals during the dialogue meeting. This is, however, a topic where researchers, at least at that time, know little about; little is known as to why it occurs more in some patients as compared to others, and what (kind of) therapy is most effective. With respect to the research system, this limited research activity on this topic seems to be caused by the high degree of specialization and the disciplinary approach of research and care. Research on burns is typically the domain of biomedical researchers and burn surgeons. From their perspective, issues like wound healing, infection/inflammation and scar development are of particular interest. A symptom like itching does not belong to their area of specialization. Therefore, we would conclude that the involvement of burn survivors on decision-making regarding burn research did have an added value, especially by pinpointing at research areas currently receiving limited attention.

A similar value of patient participation has also been witnessed in other comparable research agenda-setting projects. People suffering from asthma/COPD[3] exclusively brought up research topics, such as co-morbidity and drug interactions [2,20]. An explanation of the chairman of the research committee of the Asthma Foundation was that due to the strong disease orientation of both care and research these subjects were out of their ‘view’. An agenda-setting project with people with a congenital heart condition, executed in collaboration with the Dutch Heart Foundation, showed that research was mainly focused on intervention of the heart and

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[3] COPD = chronic obstructive pulmonary disease, previously also called lung emphysema.

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heart failure. Patients and parents were mostly interested in what the consequences were of the interventions and what they could or could not do in daily life. There was surprisingly little scientific knowledge about these topics [21]. Other projects also showed that high priority was given by patients to rehabilitation and socio-psychological aspects of the disease (e.g. Ref. [22]). Research in these fields is hardly conducted, mainly because of a lack of a researcher community. Scientists primarily focus on interventions in clinical practice, while health professionals in the field of, e.g. rehabilitation do not have a strong research tradition.

But what happened with the results of the project; was there any follow-up? After the BhURN project the research programme coordinator of NBS translated the results into a program proposal. She compared research topics in the top 15 with current research topics financially supported by the NBS. Various topics coincided with current research, particularly research on tissue regeneration and scar management. Besides, there were also 'new' topics in the top 15 compared to currently supported research, such as itching and oedema on scars and donor places, and topics in the field of rehabilitation. The research programme coordinator proposed that apart from the already financed research topics, which were legitimated by the results of the BhURN project, more attention should be paid to the topics in the top 15 that were currently hardly researched. The Director of the NBS accepted this proposal. A pilot funding program was established for under-developed research areas. Various rehabilitation researchers seized this opportunity and submitted proposals. Apart from activities of the NBS, researchers also took action themselves. Inspired by the dialogue meeting, itching was included as a parameter in a long-term epidemiological research project among burn survivors. This would provide information on when, how long, how severe and in which patients itching occurs. Also the VMB picked up some points raised during the dialogue meeting. For example, they further investigated the possibilities of establishing a buddy system as a way to assist burn survivors with respect to the observed lack of psycho-social aftercare. Early 2008 they conducted a needs assessment study among their members, which indicated the broad felt need for this kind of informal support. On short term a pilot project will start in one of the burn centres. This shows that also ideas not directly related to research can be used for follow-up activities and contribute to the improvement of the quality of life of those that it is all about—burn survivors.

Conflict of interest statement

None of the authors has any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work.

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REFERENCES

[1] Boote J, Telford R, Cooper C. Consumer involvement in health research: a review and research agenda. Health Policy 2002;61:213–36.

[2] Caron-Flinterman JF, Broerse JEW, Teerling J, Van Alst MLY, Klaasen S, Swart LE, et al. Patient participation in health research agenda setting: the case of asthma and COPD research in the Netherlands. Science and Public Policy 2006;33(4):291–304.

[3] Oliver S, Clark Jones C. Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. Health Technology Assessments 2004;8(15):1–148.

[4] RGO. Patiëntenparticipatie in gezondheidsonderzoek (Patient participation in health research). Den Haag: Raad voor Gezondheids Onderzoek; 2007.

[5] Abma T, Broerse J. Patient participation as dialogue: setting research agendas. Health Expectation; in press.

[6] Abelson J, Forest PG, Eyles J, Smith P, Martin E, Gauvin FP. Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. Social Science & Medicine 2003;57:239–51.

[7] Caron-Flinterman F. A new voice in science. Patient participation in decision making on biomedical research. Zutphen: Wohrman Print Service; 2005.

[8] Entwistle VA, Renfrew MJ, Yearley S, Forrester J, Lamont T. Lay perspectives: advantages for health research. British Medical Journal 1998;316:463–6.

[9] Caron-Flinterman JF, Broerse JEW, Bunders JFG. The experiential knowledge of patients: a new resource for biomedical research? Social Science and Medicine 2005;60:2575–84.

[10] Nordin I. Expert and non-expert knowledge in medical practice. Medicine Health Care and Philosophy 2000;3:297–304.

[11] Telford R, Beverley CA, Cooper CL, Boote JD. Consumer involvement in health research: fact or fiction? British Journal of Clinical Governance 2002;7(2):92–103.

[12] Caron-Flinterman JF, Broerse JEW, Bunders JFG. Patient partnership in decision-making on biomedical research: changing the network. Science Technology & Human Values 2007;32(3):339–68.

[13] Guba EG, Lincoln YS. Fourth generation evaluation. Beverly Hills; 1989.

[14] Stake RE. To evaluate an arts program. In: Stake RE, editor. Evaluating the arts in education: a responsive approach. Colombus Ohio: Merrill; 1975. p. 13–31.

[15] Stake RE. Standards-Based and Responsive Evaluation. Thousand Oaks: CA Sage; 2004.

[16] Flinterman JF, Teclemariam-Mesbah R, Broerse JEW, Bunders JFG. Transdisciplinarity: the new challenge for biomedical research. Bulletin of Science Technology and Society 2001;2:253–66.

[17] Greene JC, Abma TA. Responsive Evaluation. New Directions for Evaluation 2001;92:1–105.

Please cite this article in press as: Broerse JEW, et al. Involving burn survivors in agenda setting on burn research: An added value?. Burns (2009), doi:10.1016/j.burns.2009.04.004

[18] Koch T. Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. Journal of Advanced Nursing 1996;24:174–84.

[19] Van Rensen JML, De Haan MJM, Broerse JEW, Zweekhorst MBM, Hijlkema S, Raven M. Agenda wetenschappelijk brandwondenonderzoek 2007–2010. In: Het 'BhURN-project'. Beverwijk en Amsterdam: Nederlandse Brandwonden Stichting en Vrije Universiteit Amsterdam; 2007

[20] Caron-Flinterman JF, Broerse JEW, Teerling J, Bunders JFG. Patients' priorities concerning health research: the case of asthma and COPD research in The Netherlands. Health Expectations 2005;8(3):53–263.

[21] Elberse JE, Caron-Flinterman JF, De Cock-Buning T. Naar een gezamenlijke visie op onderzoek bij kinderen met een aangeboren hartafwijking. Amsterdam: Athena Institute: Vrije Universiteit Amsterdam; 2007

[22] Abma TA. Patient participation in health research. Research with and for people with spinal cord injuries. Qualitative Health Research 2005;15(10):1–19.

Please cite this article in press as: Broerse JEW, et al. Involving burn survivors in agenda setting on burn research: An added value?. Burns (2009), doi:10.1016/j.burns.2009.04.004