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# Outcomes that matter most to burn patients: A national multicentre survey study in the Netherlands

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Abbreviations: ICF, International Classification of Functioning Disability and Health; PROM, Patient-reported outcome measure

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## ABSTRACT

**Background:** The use of patient-reported outcomes to improve burn care increases. Little is known on burn patients' views on what outcomes are most important, and about preferences regarding online Patient Reported Outcome Measures (PROMs). Therefore, this study assessed what outcomes matter most to patients, and gained insights into patient preferences towards the use of online PROMs.

**Methods:** Adult patients ( $\geq 18$  years old), 3–36 months after injury completed a survey measuring importance of outcomes, separately for three time periods: during admission, short-term (< 6 months) and long-term (6–24 months) after burn injury. Both open and closed-ended questions were used. Furthermore, preferences regarding the use of patient-reported outcome measures in burn care were queried.

**Results:** A total of 140 patients were included (response rate: 27%). 'Not having pain' and 'good wound healing' were identified as very important outcomes. Also, 'physical functioning at pre-injury level', 'being independent' and 'taking care of yourself' were considered very important outcomes. The top-ten of most important outcomes largely overlapped in all three time periods. Most patients (84%) had no problems with online questionnaires, and many (67%) indicated that it should take up to 15 minutes. Patients' opinions differed widely on the preferred frequency of follow-up.

**Conclusions:** Not having pain and good wound healing were considered very important during the whole recovery of burns; in addition, physical functioning at pre-injury level, being independent, and taking care of yourself were deemed very important in the short and long-term. These outcomes are recommended to be used in burn care and research, although careful selection of outcomes remains crucial as patients prefer online questionnaires up to 15 minutes.

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## 1. Introduction

Substantial improvements in burn care and treatment have led to a shift in focus from short-term critical care outcomes towards longer-term patient-reported outcomes [1–3]. A wide range of patient-reported outcomes, including short- and long-term consequences on physical, psychological and social functioning, have been assessed in burn care and research [2–10]. Outcomes that matter most to patients are recommended to be used to systematically evaluate burn care and quantify the outcome of different treatment strategies to support care improvements and increase patient value [11–13]. In addition, insights in these patient-relevant outcomes of different treatments can be used to inform patients better on expected outcomes of different treatment options that are of value to them [14]. This supports patients to discuss with their caregiver what treatment best meets their values and support shared decision making [15–17].

The importance and use of patient-reported outcomes is widely acknowledged, however, the application in studies and implementation in burn care is an ongoing process encountering some barriers and difficulties [4,5,18–22]. Currently, little is known on patients' views and preferences on the use of (online) questionnaires and frequency of follow-up within burn care [18,23]. Furthermore, patient-reported outcomes as well as Patient-Reported Outcome Measures (PROMs) are usually chosen by clinicians and/or researchers with limited or no involvement of patient (representatives)

themselves. It is therefore unknown how important these outcomes are to patients. In order to prioritize and improve patient value in burn care, it is crucial to assess the outcomes that matter most to patients, rather than assessing outcomes that are of most interest to clinicians or researchers, or those which they believe are most important to patients [13,21]. Besides, by determining outcomes that matter most to patients, healthcare professionals and researchers can be directed to include these outcomes when setting care and research priorities.

Some studies investigated burn patients' views on important outcomes with a special focus on distress [24,25]. Main reasons for distress varied among different patient groups, with the main source of distress ranging from chronic physical discomfort to psychosocial discomfort and social and future concerns [24]. The study of Askay et al. showed that financial concerns and long recovery time were the principal concerns in both the short and long-term in an American setting [25]. However, studies show the importance of studying a broad range of outcomes at various points in the recovery of burns, as the importance of specific outcomes can change over time [24–26]. It is unknown whether these findings are generalised to other countries, like the Netherlands. Therefore, it is important to focus on the whole patient population, not only patients who are experiencing distress, and include a broad range of outcomes covering all health-related domains. The aims of this study were to assess what outcomes matter most to patients in their recovery from burns, separately for three time periods, during burn centre

admission, short-term (<6 months) and long-term (6–24 months) after burn injury, and to gain insight into patient preferences towards the use of online PROMs.

## 2. Materials and methods

This cross-sectional survey study was approved by a central Medical Ethical Committee (MEC-U; number W21.305) and by the institutional review boards of the three participating hospitals. It was conducted in line with the principles of the Declaration of Helsinki. Patients provided informed consent before participating in this study.

### 2.1. Study population

Adult patients ( $\geq 18$  years old), 3–36 months after burn, who were treated as an in- or outpatient in a Dutch burn centre (Maastad Hospital Rotterdam, Martini Hospital Groningen, Red Cross Hospital Beverwijk) were identified from the hospital's electronic patient registry in February 2022. All patients were eligible for participation. To be inclusive and include a representative sample of patients, 58 non-native Dutch/English speaking patients or patients with an expected limited health literacy were identified by their healthcare providers and invited to complete the survey via the telephone. From the remaining selection, a sample of 453 patients was randomly selected. These patients were invited to complete the survey in February 2022.

### 2.2. Study procedure

Patients of whom an email address was available in the hospitals' electronic patient registries were invited to complete the survey online. Patients of whom no email address was available received an invitation and postal survey. Patients who were unable to fill in the survey themselves; either non-native Dutch/English speaking patients who had insufficient knowledge of the Dutch or English language to answer the survey, and patients who had an expected limited health literacy – based on the experiences of their healthcare providers with these patients struggling to fill in surveys during their treatment – were telephoned and invited to participate. To all patients the rationale, aim and importance of the study was explained. Before completing survey questions, patients had to give informed consent, either digitally before starting the online survey, in writing by checking a consent box before completing the postal survey, or verbally before answering the survey questions by telephone.

The invitation, survey and informed consent form were available in Dutch and English. The survey consisted of 26 questions containing a total of 107 items that were answered anonymously. A reminder to complete the survey was sent via email or post to all patients after two weeks. If patients were willing to answer the survey questions by telephone, the questions were asked promptly or at a later agreed moment, with a translator and/or family member present if needed. In case patients could not be reached at first try, they were contacted on at least one other occasion in the following four weeks.

### 2.3. Survey

The survey included questions on patients' and clinical characteristics. Patients were asked, but not obligated, to report their age, sex, percentage Total Body Surface Area (%TBSA) burned, length of hospital stay, whether they had surgery for their burn(s) (yes/no), and the time since injury.

#### 2.3.1. Outcomes that matter most to patients

2.3.1.1. *Open-ended questions.* The survey started with an open-ended question: 'What was most important in your recovery from burns?'. This question was asked separately for three often used time periods in the recovery of burn injuries: during admission, short-term (<6 months) and long-term (6–24 months) after burn [27]. Patients were instructed to only answer questions that were relevant for them: e.g. patients who were not admitted did not complete the 'during admission' questions; patients who were <6 months after burn did not complete the long-term question.

2.3.1.2. *Closed-ended questions on predefined outcomes.* The survey also included closed-ended questions, which followed after the open-ended questions, about the importance of predefined patient-reported outcomes (Appendix A1). To limit the burden for patients who completed the survey by telephone, these questions were optional.

The International Classification of Functioning Disability and Health (ICF) framework was used as a basis for these predefined outcomes [28,29]. ICF classifies health and health-related domains and describes a health condition at body, individual and population level [29]. It includes impairment in body functions, body structures, activity and participation, and environmental factors. The ICF framework was used to ensure that all relevant domains were included in the survey. Relevant items in the ICF domains were based on literature review and often used questionnaires in the field of burns and health [5,27,30,31], and subsequently selected in close collaboration with patients, experience experts, the Dutch Association of Burn Survivors and healthcare professionals (Appendix A1). For each predefined outcome, patients indicated the importance of that outcome in their recovery on a 4-point Likert scale ranging from 'not important' to 'very important', and the option 'not applicable/don't know'. This was separately asked for the three different time periods.

#### 2.3.2. Use of online PROMs in burn care

The use of online PROMs in patient burn care was explained and followed by a question about the difficulty of completing an online questionnaire consisting of PROMs to be used in the patients burn care. They were also asked about the preferred duration. The six answer options ranged from 5 to 45 minutes, and patients could indicate 'other, namely' to elaborate on another preference. Also, the frequency of such a questionnaire, separately for the three different time periods was asked. Answer options included 'daily/weekly/once/other, namely' for during admission; 'weekly/monthly/once/before every consultation/other, namely' for the period up to six months; 'monthly/every three months/every six months/before every consultation/other, namely' for the period 6–24 months.

## 2.4. Statistical analyses

Patients were included when they completed the open-ended questions on most important outcomes and the questions regarding the use of online PROMs in burn care. Patient and clinical characteristics were assessed using descriptive statistics. Continuous data were reported as mean (SD) if normally distributed, and as median (IQR) if not-normally distributed. Categorical data were reported as numbers (percentage). Characteristics were compared between participants who completed the survey online/on paper versus participants who completed the survey via telephone. Mann-Whitney U-tests were used for continuous variables; chi-square tests for categorical variables, except for comparison of groups with small numbers ( $n < 5$ ), then the Fisher's exact test was applied.

A mixed method of a deductive and inductive approach was used for analysing the open-ended questions by three researchers [32]. Open-ended responses on outcomes that patients reported as being most important were categorized into the predefined closed questions items, and four new categories were defined based on the responses that could not be categorized in the predefined items. Subsequently, results were ranked on the number of times a specific outcome was reported as being most important. This was done separately for each of the three time periods studied. Results were compared between non-native Dutch/English speaking patients/patients with an expected limited health literacy and other patients.

Closed-ended questions on predefined outcomes that matter most to patients were studied using frequencies and rankings, separately for the three different time periods. Predefined outcomes were ranked on the percentage of patients that scored an outcome as 'very important'. These outcomes were studied for the total population as well as for subgroups based on age ( $< 65$  vs.  $\geq 65$  years old), on having received surgery (no surgery vs.  $\geq 1$  surgery), and on burn centre admission (no admission vs.  $\geq 1$  day stay). Chi-square tests were used to analyse and compare outcomes. The Fisher's exact test was applied for comparison of groups with small numbers ( $n < 5$ ). Python 3.10 was used for the quantitative analyses.

## 3. Results

In total, 511 patients were selected from the registry of whom 140 (response rate: 27%) completed at least the open-ended questions. Questions were completed online/on paper ( $n = 122$ , response rate: 27%) or via telephone ( $n = 18$ , response rate: 31%). From all respondents, 120 patients (86%) answered the Dutch survey, 12 patients (9%) were interviewed by telephone because of limited health literacy, six patients (4%) were interviewed by telephone because they were non-native Dutch or English speaking, and two persons (1%) answered the English survey. In total, 112 patients (80%) completed the questions about their characteristics. Of these patients, most were male (62%) and the median age was 53 years (IQR: 43–64) (Table 1). Median %TBSA burned was 9% (IQR: 5–20%), most of the patients were admitted to a burn

centre (73%) with a median length of stay of 14 days (IQR: 3–23 days). Almost half of the patients underwent surgery for their burns (45%) and the median time since burn injury was 16.5 months (IQR: 10.0–24.0 months). Characteristics did not statistically significantly differ between participants who completed the survey online/on paper versus participants who completed the survey via telephone ( $p > 0.05$ ).

### 3.1. Outcomes that matter most to patients

#### 3.1.1. Open-ended question results

Four additional outcomes, that were not part of the list of predefined outcomes, were identified by analysing the open-ended questions. These included 'quality of care and engagement of healthcare providers' (e.g., attention for you as a unique human being, and the perceived high level of care), 'good rehabilitation care and aftercare' (e.g., receiving the required care, and the ability to ask questions at any time), 'physical functioning at pre-injury level' (e.g., being able to do my daily activities again), and 'mental well-being and recovery' (e.g., complete mental recovery to pre-injury level).

During admission, 'quality of care and engagement of healthcare providers' was considered most important by many patients (40%). Followed by 'not having any pain' (22%), 'good wound healing' (19%) and 'physical functioning at pre-injury level' (19%) (Table 2). Outcomes that were considered most important were similar for the short- and long-term recovery of burns, however, their ranking differed (Table 3). 'Good rehabilitation care and aftercare' was most often reported as most important in the short-term ( $< 6$  months after burn; 34%) and was second most often reported as most important in the long-term (6–24 months after burn; 18%). 'Physical functioning at pre-injury level' was third most often reported as most important in the short-term (24%) and most often in the long-term (34%). 'Good wound healing' and 'mental wellbeing and recovery' were in the top-five in both time periods. 'Look/appearance of scar(s)' was only in the top-five in the long-term (Table 2).

We compared the results between non-native Dutch/English speaking patients or patients with an expected limited health literacy (patients who answered the survey by telephone;  $n = 18$ ) and other patients (those who answered the postal or online survey;  $n = 122$ ) to examine whether their most important outcomes differed. Barely any differences were encountered, with the most important outcome being identical for both groups for all three time periods (data not shown).

#### 3.1.2. Closed-ended questions on predefined outcomes results

A total of 126 patients (90%) completed at least one of the closed-ended questions on predefined outcomes, including 10 patients who answered the questions via telephone. During admission, wound care and wound healing was considered most important, with the outcomes 'receiving good wound treatment' (88% of the patients scored this outcome as 'very important'), 'good wound healing' (84%), and 'not having a wound infection' (84%) being the top-three most important outcomes (Table 3; Appendix A2). The order of top-three of most important outcomes was identical in the short-

**Table 1 – Patient characteristics.**

Variable	Total sample	Participants who completed survey online/on paper	Participants who completed survey via telephone	p-value for difference
Sex: Male, n(%)	69 (61.6%)	57 (60.6%)	12 (66.7%)	0.630
Age at survey, median (IQR)	52.5 (43.0–64.2)	54.5 (43.0–66.0)	44.5 (36.5–56.8)	0.097
%TBSA burned, median (IQR)	8.5 (4.8–20.0)	10.0 (5.0–21.0)	7.0 (3.0–18.0)	0.318
Hospital admission, n(%)	82 (73.2%)	66 (70.2%)	16 (88.9%)	0.147
Length of hospital stay (days), median (IQR)	14.0 (3.0–23.0)	12.0 (3.8–21.5)	15.0 (3.0–28.0)	*
Surgery, n(%)	50 (44.6%)	39 (41.5%)	11 (61.1%)	0.101
Time since burn (months), median (IQR)	16.5 (10.0–24.0)	18.0 (8.0–25.0)	12.0 (10.0–19.0)	0.301
Type of survey:				
Dutch survey	120 (85.7%)	120 (98.4%)		
English survey	2 (1.4%)	2 (1.6%)		
Limited health literacy	12 (8.6%)		12 (66.7%)	
Not native speaking Dutch/English	6 (4.3%)		6 (33.3%)	

\* There are not enough cases to perform Mann-Whitney U test

and long-term (Table 3; Appendix A3–4). ‘Good wound healing’ was considered the most important outcome at both < 6 months (84%), and 6–24 months after burn (72%). ‘Being independent’ was considered the second most important outcome (72–76%); and ‘taking care of yourself’ the third most important outcome (73–74%) in these time periods. Some outcomes, including ‘interacting with family’, ‘walking or moving around’, and ‘trusting your body’ were comparably important in all three phases of recovery from burns, with ‘interacting with family’ being ranked top 5–7 (59–65%), ‘walking or moving around’ being ranked top 4–7 (62–68%), and ‘trusting your body’ being ranked top 7–10 (55–64%). ‘Sleeping well’ increased in importance, from being ranked eight (61%) during admission to fourth (69%) in the long-term. ‘Having energy’ was especially considered important in the later phases (> 6 months) of the burn recovery (66%).

### 3.1.3. Comparison of subgroup results

3.1.3.1. *Age.* During admission and for the short-term, the top-three of most important outcomes was identical, though the order differed between both age groups (Appendix A5). For the long-term, the top-three differed, with ‘having energy’ (81%) being considered very important by many older patients (≥65 years old), whereas it seems less important to younger patients (< 65 years old). For both the short- and long-term ‘fine motor skills’ was in the top-5 for the older age group, but not for the younger patients. In contrast, ‘walking or moving around’ was in the top-five in all time periods for younger patients, but not for older patients.

3.1.3.2. *Surgery.* Patients who did not have surgery for their burns had the same outcomes in the top-three during admission and for short-term recovery as patients who did have surgery (Appendix A6). The top-three in the longer-term differed slightly. Remarkable was that the proportion of patients reporting a specific outcome as very important was much higher for patients who had surgery compared to those who did not had surgery, showing that the most important outcomes were very important to a larger part of the patients

with surgery compared to patients without surgery. Furthermore, interacting with partner and family was in the top-five at each period for those without surgery, but did not appear in the top-5 for those with surgery. Outcomes in the top-5 for patients who had surgery were more focused on physical recovery.

3.1.3.3. *Admission.* For both the short- and long-term, the top-three of most important outcomes differed slightly between patients who were and were not admitted to a burn centre (Appendix A7). More mental health orientated outcomes, like ‘trusting your body’ and ‘having self-confidence’ were very important for many patients without a burn centre admission. For patients who had a burn centre admission, more physical health orientated outcomes seem to be more important, like ‘being independent’, and ‘taking care of yourself’.

## 3.2. Use of online PROMs in burn care

All patients (n = 140) completed the questions on the use of online PROMs in burn care. Most patients (84%) indicated that they had no difficulties with completing an online PROMs questionnaire to be used in their burn care. However, 23 patients (16%) indicated that completing an online questionnaire was too difficult (n = 12), not relevant (n = 7) or causes too much distress for them (n = 4). The majority of the patients reported that they prefer a questionnaire that take maximum 10–15 minutes (67%) to complete. Some indicated a shorter duration of about 5 minutes (22%), and few a longer duration of ≥ 20 minutes (11%).

Patients highly differed in their preference regarding the frequency of completing a questionnaire. During admission many patients preferred to complete a questionnaire once (43%); some preferred weekly (30%); and only a few daily (6%) or monthly (4%). Eight percent of patients preferred other frequencies, and another 8% of the patients reported that they preferred not to complete any questionnaire during admission. In the period up to six months after burn, many

**Table 2 – Top-5 most important outcomes at each assessment moment based on open-ended question responses.**

During admission		after < 6 months after burn		6–24 months after burn		% <sup>a</sup>		
1	Quality of care and engagement of healthcare providers <sup>b</sup>	40.3	1	Good rehabilitation care and aftercare <sup>b</sup>	33.6	1	Physical functioning at pre-injury level <sup>b</sup>	33.7
2	Not having any pain	22.4	2	Good wound healing	30.0	2	Good rehabilitation care and aftercare <sup>b</sup>	18.1
3	Good wound healing	19.4	3	Physical functioning at pre-injury level <sup>b</sup>	23.5	3	Look/appearance of scar(s)	16.9
3	Physical functioning at pre-injury level <sup>b</sup>	19.4	4	Not having any pain	7.6	4	Mental wellbeing and recovery	13.3
5	Not being anxious	9.0	5	Mental wellbeing and recovery	7.6	5	Good wound healing	10.8
5	Mental wellbeing and recovery	9.0						

<sup>a</sup> The percentage represents the proportion of patients that reported an outcome as 'most important' to them.

<sup>b</sup> Outcomes added to predefined outcome list based on open-ended responses.

**Table 3 – Top-10 most important outcomes at each assessment moment based on closed-ended question responses on predefined outcomes.**

During admission		< 6 months after burn		6–24 months after burn		% <sup>a</sup>		
1	Receiving good wound treatment	88.2	1	Good wound healing	84.3	1	Good wound healing	72.1
2	Good wound healing	84.0	2	Being independent	76.2	2	Being independent	71.8
2	Not having a wound infection	84.0	3	Taking care of yourself (washing, dressing, eating, drinking, etc.)	73.8	3	Taking care of yourself (washing, dressing, eating, drinking, etc.)	70.6
4	Taking care of yourself (washing, dressing, eating, drinking, etc.)	66.7	4	Walking or moving around	68.2	4	Sleeping well	69.4
5	Interacting with my family	64.8	5	Sleeping well	67.5	5	Having energy	65.9
6	Being independent	63.9	6	Interacting with family	65.4	6	Walking or moving around	63.5
7	Walking or moving around	61.8	7	Trusting your body	63.8	7	Having self-confidence	59.0
8	Sleeping well	61.3	8	Being able to think well (such as focusing or remembering)	63.2	7	Interacting with family	59.0
9	Fine hand motor skills (e.g. holding a pen or buttoning a shirt)	56.8	8	Fine motor skills of the hands (e.g. holding a pen or buttoning a shirt)	63.2	9	Trusting your body	58.5
10	Trusting your body	54.7	10	Having self-confidence	63.0	10	Being able to think well (such as focusing or remembering)	57.8

<sup>a</sup> The percentage represents the proportion of patients that indicated that an outcome was 'very important' to them

patients preferred to complete a questionnaire only once in these six months (44%); 22% preferred monthly; 13% before a consultation; 10% weekly; and 8% not at all. For the long-term, 27% preferred every six months; 20% before every consult; 16% every three months; 13% not at all; and 11% once.

#### 4. Discussion

This study investigated what outcomes are most important to adult burn patients. 'Not having pain' and 'good wound healing' were identified as very important outcomes in both the open and closed-ended questions. Also, the importance of 'physical functioning at pre-injury level' as indicated in the open-ended questions is in line with 'being independent' and 'taking care of yourself', which were considered very important outcomes in the short- and long-term closed questions, confirming the overall importance of these outcomes to burn patients. Interestingly, the top-ten of most important predefined outcomes largely overlapped in all three time periods, showing that most important outcomes are relevant during the whole recovery from burns injuries. It is therefore important to have a longitudinal focus on these outcomes in burn care. Important outcomes were comparable for patients with and without language difficulties, indicating that universal outcomes matter most for patients independent of health literacy or language differences. Furthermore, the importance of outcomes barely differed between subgroups based on age, surgery and admission. This study also provided insights into burn patients' views and preferences on the use of online PROMs. This seems to be a good approach for most patients; however, one out of six patients encounter some problems with online PROMs. In general, patients indicated that an online questionnaire should not take longer than 15 minutes and patients' opinions differ widely on the preferred frequency of follow-up.

Four additional outcomes were identified from the open-ended questions. Two of these items were related to quality of care, which are strictly not outcomes according to the ICF framework, but environmental factors; i.e. factors influencing outcomes [29]. Nevertheless, patients reported these factors often as very important, highlighting the importance of quality of care to patients. These factors are in line with the burn care professionals' most relevant quality indicators, which include availability of intensive care, burn surgeons, and dedicated burn care nurses, as well as 24-hours access to burn services [33]. Our findings also indicates the difficulty of using open-ended questions for such specific questions. This was also highlighted by the fact that many patients reported generally formulated answers, which were often related to general well-being and recovery and could not be categorized into our predefined more detailed outcomes. This finding corresponds with the recent tendency towards using more generic outcomes instead of disease specific outcomes in other fields and nationwide initiatives, like the Dutch value based healthcare and shared decision making initiative [34]. Recent evidence suggests that outcomes that matter most to patients are often found to be not disease specific and overlap highly between diseases [35–37]. For example, pain,

physical function, fatigue, mental health and social function are outcomes that are relevant to everyone, irrespective of the disease. Also, the fact that none of the scar-related outcomes ended up in the top-ten most important outcomes in the closed-ended questions at any time point supports this more generic approach. Still, 'good wound healing', which is related to scar quality and to function, was considered most important in all three time periods. Our results thus seem to suggest that function and wound healing on itself seem to be of more importance to patients than scar-specific outcomes. The importance of scar-related outcomes is also interesting when comparing the most important outcomes according to patients with preferences of burn care professionals. While patients did not consider scar-related outcomes being one of the most important outcomes, burn care professionals often do and its importance is acknowledged by a number of groups around the world [13,21]. Comparing these outcomes raise the question if measuring scar outcomes is what patients value most. However, this might be slightly affected by the time since injury of our participants (median 16.5 months); longer after burns, scars might become more important, and scar-specific outcomes might be more relevant to patients with severe burn injuries.

Some mental health outcomes were considered very important by a large part of our sample, including the outcomes 'trusting your body', and 'having self-confidence', as well as the cognitive outcome 'being able to think well'. However, other mental health outcomes were less often considered as being 'very important' including 'feeling happy or cheerful' during admission, and 'not thinking back to the accident' and 'not feeling guilty or ashamed' in each time period, as well as some more social related outcomes, including 'returning to school' and 'interacting with your boss'. As the latter two might be only relevant to a (small) part of the population, this should be kept in mind when considering the use of these outcomes. Although attention should be paid to the outcomes that were considered very important by most patients when selecting PROMs for population-based analyses, outcomes are patient specific and therefore it is important to also consider the most important outcomes and recovery goals for a specific patient in burn care.

A few minor differences were observed when comparing results between subgroups. In the long-term, older patients indicated 'having energy' and 'fine motor skills' as being very important, whereas for younger patients 'walking and moving around' was more important. Patients without surgery found 'interacting with partner and family' very important, whereas patients who had surgery seemed to be more focused on physical recovery. This difference might be related to the severity of burn injury; patients with more severe burns have a prolonged recovery and generally more physical problems [38–40]. Severity of burn injury may also cause the small differences seen between patients with and without a burn centre admission. Outcomes related to mental functioning, like 'trusting your body', seem to be somewhat more important for those not admitted, whereas, more physical outcomes, like 'being independent' seem to be more important for admitted patients. This difference could be influenced by difference in time after burn of patients that completed our questionnaire, as earlier reviews showed that

mental problems tend to develop later in the recovery from burns and are strong predictors for diminished quality of life [27,41]. However, time since injury was statistically significantly longer for admitted patients in our study, and can therefore not explain the difference in importance of outcomes related to mental functioning.

With the increased focus on patient-reported outcomes in burn care and research, the use of PROMs increases [4,5,27,42]. Most patients indicated that a questionnaire should not take longer than 15 minutes. However, in practice, questionnaires often take a longer time to complete. Also in other patient groups, the duration of questionnaires is an often-encountered barrier [43–46]. A previous study recommended to overcome this barrier by limiting the duration of a questionnaire to a maximum of 10 minutes and to use an electronic device [43]. Patients might be more willing to complete a (longer) questionnaire when receiving good explanation of the use of the results from a healthcare provider. Within burns, there is no clear preferred mode of administration of PROMs [18], however our study shows that using online PROMs is a good approach for most patients. An increasing number of studies and registries seem to embrace digital questionnaires [18,22,23,47] and recently Meirte and Tyack published a guide on the implementation of electronic PROMs for burn scar rehabilitation [13]. However, in our study, 17% of patients indicated to encounter problems, of whom 8% indicated that completing an online questionnaire is too difficult. In order to be inclusive in burn care, it is very important to offer those patients extra support and alternative administration options.

Another often encountered barrier in the use of PROMs is the high lost to follow-up [18–20,48,49]. A patient-centred frequency, i.e., a frequency that is tailored to an individual patient's preferences, might be a possibility to deal with the large variety in preferred frequencies between patients. Gabbe et al. highlighted that tailoring the frequency of follow-up should be given greater consideration [18]. Another possibility is to use set time points based on the preferences of most patients. With our study results in mind, these may be once during admission, once in the first six months after burn and then every six months up to two years after burn. With the added option for patients to indicate if they prefer to complete a follow-up questionnaire more often.

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## 5. Strengths and limitations

Strengths of our study include the inclusion of non-native Dutch/English speaking patients and patients with limited health literacy, the multicentre approach, and the use of a variety of methods. By both using telephone interviews and postal and online surveys we were able to be more inclusive, and by both open- and closed-ended questions we generated a comprehensive overview of important outcomes to patients. However, the number of non-native Dutch/English speaking patients and patients with limited health literacy was a small group of our total sample. The response rate of our study was 27% which may have introduced response bias as only a part of the invited patients completed the questionnaire. This may limit the generalizability of our results.

However, this was the first study to investigate this important topic in the Dutch context providing new important insights. Other limitations include that we asked patient about difficulties with completing an online questionnaire in a postal or online questionnaire and by telephone interviews. This might lead to an underestimation of the perceived difficulties with completing an online questionnaire. Besides, we did not register whom completed the questionnaire online and whom completed it on paper. Postal survey answers were entered by staff in the same platform as in which patients completed the online survey. Besides, due to the low number of patients who completed the closed-ended questions via the telephone, we were unable to compare outcomes between telephone responses and other responses. Also, we were unable to conduct a non-response analysis as we were unaware of the characteristics of non-responders. And, the majority of our sample experienced mild or intermediate burns; our results might therefore not be fully generalizable to adults with major burn injuries. In addition, questions for specific parts of the survey, e.g., during admission, were answered later in time. Patients' perspectives might have been changed in the meantime and slight recall bias (e.g. remembering outcomes as worse than they actually were) could have been introduced [50]. Another limitation might be the Dutch context; e.g., the importance of return to work might be highly influenced by the availability of social support in a country.

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## 6. Conclusions

The present study identified outcomes that matter most to burn patients. 'Not having pain' is very important during admission; 'good wound healing', 'taking care of yourself', 'being independent' and 'physical functioning at pre-injury level' are considered very important during the whole recovery of burn injuries. These outcomes are recommended to be used to systematically evaluate burn care and quantify the results of different treatment strategies to support care improvements and increase patient value. However, careful selection of the most important outcomes is crucial as patients prefer that an online PROMs questionnaire takes up to 10–15 minutes to complete. Additionally, a patient-centred frequency might be favourable as patients' opinions differ widely on the preferred follow-up frequency. Online PROMs seem to be a good approach for most burn patients. However, nearly one out of six patients indicate having difficulties with online PROMs. In order to be inclusive and to provide optimal burn care to all burn patients, it is recommended to explore other administration options for these patients, or offer assistance during completion.

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## Ethics approval and consent to participate

This study was performed according to the principles of the Declaration of Helsinki (Ethics manual World Medical Association 2nd edition 2009), and approved by the Ethics Committee (MEC-U; number W21.305) and the institutional boards of the three hospitals. Informed consent was obtained from all individual participants included in the study.



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## CRedit authorship contribution statement

Conceptualization: IS, MB, MN, AP, IV, CS, PZ, TH, CL. Methodology: IS, DU, MB, MN, AP, CL, Formal analysis: IS, DU, LD Investigation: IS, CL Writing – original draft: IS, Writing – review & editing: DU, LD, MB, MN, AP, IV, CS, PZ, TH, CL Supervision: CL, Project administration: IS, CL, Funding acquisition: IS, MB, MN, AP, CS, PZ, TH. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

## Declaration of Competing Interest

All authors whose names are listed immediately below have no financial and personal relationships with other people or organisations that could inappropriately influence (bias) their work. Examples of potential conflicts of interest include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding.

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## Consent for publication

Not applicable.

## Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.burns.2023.10.018](https://doi.org/10.1016/j.burns.2023.10.018).

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