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# Lessons learned during the implementation of a web-based triage-tool for intensive care follow-up clinics. A mixed methods study.

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## Abstract

**Objectives:** Screening for symptoms of Post Intensive Care Syndrome is based on a long list of questionnaires, filled out by the ICU survivor and manually reviewed by the caregiver. This is an inefficient and time consuming process. The aim of this study was to evaluate the feasibility of a web-based triage-tool and to compare the outcomes from web-based questionnaires to those from paper-based questionnaires.

**Design:** A mixed methods study.

**Setting**: Nine Dutch ICU follow-up clinics.

**Participants:** 221 ICU survivors and 14 professional caregivers.

**Interventions:** A web-based triage-tool was implemented by nine ICUs. End-users, i.e. caregivers, were interviewed in order to evaluate the feasibility of the triage-tool. ICU survivors were invited to fill out web-based questionnaires 3 months after hospital discharge.

**Primary outcomes:** Outcomes of the questionnaires were merged with clinical data from a national quality registry to assess the differences in outcomes between paper-based and web-based questionnaires.

**Results:** 221 ICU survivors received an invitation to fill out questionnaires, 93 (42.1%) survivors did not respond to the invitation. Respondents to the web-based questionnaires (n=54) were significantly younger and had a significantly longer ICU stay than those who preferred the paper-based questionnaires (n=74). The prevalence of mental, physical and nutritional problems was high, although comparable between the groups. Caregiver' interviews revealed that the software was complex to use (n=8) and although e-mailing survivors is very convenient, not all survivors have an e-mail address (n=7).

**Conclusions:** Web-based screening software has major benefits compared to paper-based screening. However, implementation has shown to be rather difficult and there are important barriers to consider. Although different in age, the health status is comparable between the users of the web-based questionnaire and paper-based questionnaire.

Key words: web-based questionnaires, triage, intensive care, survivors, PICS, mixed methods

**Strengths and limitations of this study**

- A strength of this study is that we implemented the web-based triage-tool in a clinical care setting instead of a clinical trial setting.
- Outcomes and characteristics of patients which preferred the web-based questionnaires were compared with the outcomes and characteristics of patients which preferred the paper-based questionnaires.
- By using mixed methods we were able to verify the statements of caregivers with the clinical data and questionnaire outcomes of survivors.

**Funding and competing interests statement**

All the authors have declared no conflicts of interest and this research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors. None of the material from this study is included in another manuscript, has been published previously, is currently under consideration for publication elsewhere, nor has been posted on the internet.

## Introduction

Intensive Care Unit (ICU) survivors frequently suffer long-term and severe complaints after ICU discharge [1, 2] and a single term is used to identify the presence of one or more impairments after critical illness: Post Intensive Care Syndrome (PICS) [3].

Because of the complexity and magnitude of the complaints, multidisciplinary care after ICU discharge is required [4]. ICU follow-up care aims to detect PICS in an early stage and the ICU survivors will be referred to the appropriate caregiver(s) during consultation. In some ICU guidelines it is recommended to have a post-ICU clinic [5].

Generally, screening for symptoms of PICS is based on a long list of paper-based questionnaires, filled out manually by the survivor and reviewed by the caregiver before or during consultation. This is an inefficient and time consuming process. Moreover, there is a high rate of non-responders due to the age and medical conditions of survivors and because survivors cannot always be traced on their home address [6, 7].

We created a web-based triage-tool to collect patient-reported screening data. The tool supports automatic processing of the data before presenting it to the caregiver. Web-based screening has major benefits compared to paper-based screening, for example more complete data, less entry errors and easy storage of data [8], leading to enhanced integrity and accuracy of outcome data [9]. In previous literature the benefits of web-based screening software has been pointed out in clinical trial settings [10]. However, research on the implementation of software in clinical care and the use of web-based screening in ICU survivors and ICU personnel is scarce.

The aim of this study was to evaluate the feasibility of our web-based triage-tool in the ICU and to assess the outcomes gained by a web-based questionnaire compared to those from conventional paper-based questionnaires.

## Materials and methods

*Setting*

Based on the recommendations of Van der Schaaf et al. [11] (table 1), a new web-based triage-tool was created and tested during a pilot-study. The tool supports automatic collection and processing of data for post-ICU care. The study was conducted between the 1st of June 2014 and the 30th of June 2015. All ICUs participating in the Dutch National Intensive Care Evaluation (NICE) registry that had a post-ICU clinic were invited to participate in this pilot-study. The NICE registry is a quality registry which contains demographic data, physiological data and clinical data for all ICU patients in the Netherlands [12, 13]. We aimed to include 10 ICU's in this pilot study.

**Table 1.** Recommendations for eligibility of ICU survivors for ICU follow-up clinics [11]

- Invite all survivors who received > 48 h mechanical ventilation
- Invite the partners of survivors
- Plan the first visit to the post-ICU clinic 12 weeks after hospital discharge with the possibility for a follow-up at indication
- Screen survivors with respect to their needs and ICU related sequelae
- Use electronic patient-reported screening instruments to identify survivors in the need for post-ICU care
- Have an ICU nurse, whether or not with an intensivist, carrying out the post-ICU clinic
- Involve a physiotherapist to perform a comprehensive physical screening
- Integrate follow-up care data into a national quality registry for ICU to monitor and improve quality of life and functional status of survivors

*Web-based triage-tool*

The triage-tool includes a module for caregivers to be used in the follow-up clinics and a web-based questionnaire module for ICU survivors.

During the development of the triage-tool, both modules were tested for usability. The module for caregivers was evaluated with four caregivers by means of semi-structured interviews [14]. The usability of the web-based questionnaire module was evaluated with four ICU survivors using the Think Aloud method [14, 15]. Outcomes of the semi-structured interviews and the Think Aloud sessions resulted in minor adjustments of the triage-tool prior to implementation of the triage-tool in the pilot-study [14].

The triage-tool automatically extracted data of eligible survivors from the hospital information system (HIS). Nine weeks after hospital discharge, the caregivers received a prompt to send the survivor an invitation by e-mail to fill out a set of online questionnaires and to invite the survivor to visit the post-ICU clinic 3 months after hospital discharge. If there was no response from the survivor within the next week, the caregiver received a prompt to call the survivor. During this phone call, the caregiver would ask for the reason of the non-response and explain the importance of screening for PICS and a visit to the ICU follow-up clinic. If survivors stated that they were unable to fill out the online questionnaire, a paper-based questionnaire was issued. The paper-based questionnaires were entered in the system manually by the caregiver or the secretary.

The pilot-study included the questionnaires described in table 2. Besides these validated questionnaires, work and income related questions, common problems after ICU admission and visits to caregivers after ICU admission were queried (appendix 1).

**Table 2.** Validated questionnaires used during this study

| Name | Description | Cut-off point |
|---|---|---|
| Hospital Anxiety and Depression Scale (HADS) [16] | A 14-items screening tool consisting of two subscales which evaluate symptoms of depression (seven items) and symptoms of anxiety (seven items) | Score of >=8 to identify patients prone to develop depression or anxiety |
| Short From 36 (SF-36) [17] | A 36-item screening-tool comprising two components; a physical- and a mental component score. Component scores range from 0 to 100, with higher scores indicating better health status [18] | Score of < 40 to identify decreased physical or mental health component |
| Trauma Screening Questionnaire (TSQ) [19] | A 10-item screening tool used to identify post-traumatic stress disorder (PTSD) | Score of >=6 to identify possible PTSD |
| Malnutrition Universal Screening Tool (MUST) [20] | A 3-item screening tool to obtain the risk of malnutrition | Scores >= 1 to identify patients with a risk of malnutrition |

The results of the questionnaires were automatically processed by the triage-tool and compared to the cut-off points. During the follow-up consultation the caregiver and the survivor discussed the outcomes of the questionnaire and the survivor was referred to a specialist if necessary. This was similar to the process before the implementation of the triage-tool except for the fact that the outcomes of the questionnaires were calculated and present before the start of the consultation.

Caregivers were trained to use the software before the start of the study. The 3-hour training was given by the developers of the tool and a researcher (IvB or FBR). During the pilot-study, the caregivers were contacted regularly and offered assistance when necessary.

*Evaluation of the feasibility of the triage-tool*

After finishing the pilot-study, semi-structured interviews were conducted with caregivers who used the tool, to gain insight in the feasibility of the triage-tool. The semi-structured

interviews were hold from July 2015 until September 2015 and conducted by one researcher (IvB). All caregivers were viewed in their own working environment and an informed consent was verbally issued and recorded before the interview started.

All interviews were recorded digitally and transcribed verbatim. The Thematic Content Analysis (TCA) method was used to analyse the qualitative data [16]. All interviews were coded individually by two researches (IvB and FBR). Both researchers extracted the statements from the transcripts and grouped the statements by themes. The themes and statements were discussed until 100% agreement was achieved on the coding.

The statements of the caregivers were compared with the characteristics of the survivors and the outcomes of the questionnaires in order to relate the qualitative data to the quantitative data.

Finally, the caregivers were requested to fill out the System Usability Scale (SUS) [17]. The SUS is a tool to evaluate software tools. Scores range from 0-100 and a SUS score above 68 indicating above average usability [17].

*Questionnaire outcomes of the ICU survivors*

The outcomes of the questionnaires were used to evaluate the type and severity of symptoms of PICS present in survivors. The anonymised data of the questionnaires were linked with clinical data from the NICE registry to gain insight in the demographics and clinical differences between survivors who filled out the web-based questionnaires compared to those who filled out the paper-based questionnaires. Data-linking was based on a unique identifying number available in both databases.

Categorical data was presented as numbers and percentages, continuous data as medians and interquartile ranges (IQR). Differences between the web-based questionnaire group and the paper-based questionnaire group for non-normally distributed data were calculated using the Mann-Whitney-U test. Differences between the two groups for normally distributed data were calculated using the T-test. For categorical data, the $Chi^2$ test was used to assess the differences between the study groups. All analyses were performed using IBM SPSS Statistics version 24 [18].

**Results**

Of the 23 Dutch ICUs with an ICU follow-up clinic, nine ICUs (39.1%) participated in the pilot- study. One ICU withdrew due to reorganisation 8 months after the start of the study. Of the eight participating ICUs, 1 (12.5%) was located in an university hospital, 1 (12.5%) in a teaching hospital and 6 (75.0%) in community hospitals.

*Evaluation of the feasibility of the triage-tool*

During this pilot-study, 531 survivors were eligible for follow-up care and were extracted from the HIS. Before sending out the invitations, the caregiver would check if the survivor was still alive and 42 (7.9%) survivors were reported as 'deceased after hospital discharge'. Of the remaining survivors, 221 (45.2%) received an invitation to fill out the questionnaires and to attend follow-up care. Other reasons for not inviting the survivor, beside death, were not collected. There were no significant differences in characteristics between survivors who were invited or not.

Ninety-three (42.1%) survivors did not respond to the invitation. Twenty-eight (12.7%) non-responders were phoned by the caregiver to ask for the reason for non-response; three (10.7%) could not be reached on their phone number, eight (28.6%) said they were well and did not need follow-up care, three (10.7%) said they were unable to fill out questionnaires and to attend follow-up care due to their poor health status, two (7.1%) had no recollection of the IC admission, six (21.4%) were already involved in a rehabilitation program, one (3.6%) had no computer, and five (17.9%) gave other reasons. It is unknown whether the other 65 non-responders were not contacted or that the phone calls were not registered.

Fourteen caregivers worked with the system and were interviewed; five intensivists, six ICU nurses, one physical therapist and two medical secretaries. The duration of the interviews ranged from 21 minutes to 39 minutes. Ten caregivers filled out the SUS with an average score of 56.

Table 3 shows the main barriers for survivors not using the tool according to the caregivers. E-mail addresses of survivors or family members were not always routinely collected before the start of the study. During the study, this was implemented in the regular workflow in the HIS.

Caregivers were surprised to find out that a large part of survivors mentioned not to have an e-mail address, even the 'younger' survivors of forty to fifty years old. Over 70% of the caregivers said that the ICU population in general is older, and that survivors are not ready to use the web-based questionnaires because of their age, that survivors were too sick to fill out the questionnaires or that survivors did not want to be confronted with the ICU admission.

According to the caregivers, if follow-up care is offered on a voluntary basis, some survivors will reject it (10%). Lack of interest, avoidance as part of PTSD, distance to hospital, burden to ask caregivers for support are frequently stated reasons by the caregivers for survivors to reject post-ICU care. Most caregivers (85.7%) would like to see follow-up care as part of the routine care, only few caregivers think of the follow-up care as an extra service to the survivor.

**Table 3.** Themes exemplifying the statements of the 14 caregivers interviewed

| Themes | Statements |
|---|---|
| Personal themes | E-mailing the patient is very convenient, especially during night shifts (n=7).<br>I did not think about e-mailing the patient, I like to call patients (n=2). |
| Software related themes | The software was complex (n=8).<br>Patients' e-mail addresses were not available in the HIS at the start of the pilot, calling the patient to collect the e-mail address was very time consuming (n=8).<br>Since we used so little, I forgot how to send an e-mail with it (n=5). |
| Patient related themes | Patients did not have an e-mail address, even not the patients of 40 to 50 years old (n=10).<br>Patients are not ready to use the web-based questionnaires, in 10 years this will be different (n=10).<br>Some patients are not interested in follow-up care, sometimes they are too sick and sometimes they already have support (n=10). |
| Organization related themes | There are no resources available for follow-up care, we arranged it in our own time (n=4)<br>A follow-up consultation is not part of the 'routine care process', patients perceive it as optional and might not come (n=4). |

*Questionnaire outcomes of the ICU survivors*

In total 54 survivors filled out the web-based questionnaires and 74 survivors used the paper-based version. Eighty-seven survivors attended ICU follow-up care. Table 4 gives an overview of characteristics of survivors, grouped by paper-based or web-based data-collection. Survivors who preferred web-based questionnaires were significantly younger compared to survivors who filled out the paper-based questionnaires ($p< 0.05$), and had a longer ICU stay ($p< 0.05$). Survivors that filled out the web-bases questionnaires had a significant higher prevalence of PTSD, measured with the TSQ. For all other patient-reported outcomes, there were no significant differences between survivors which filled out the web-based questionnaires as opposed to survivors who filled out paper-based questionnaires.

In the paper-based group, less questionnaire outcomes could be calculated due to missing items, i.e. in the paper-based group 13.2% of the results were missing, in the web-based questionnaire group this was 2.8%.

Within both questionnaire groups there was a large prevalence of possible mental problems, physical problems and nutritional problems (table 4 and figure 1). Not all survivors with possible problems had contact with the appropriate healthcare professionals during the time of filling out the questionnaires.

**Table 4.** Characteristics of ICU survivors who returned the questionnaires

| | Web-based questionnaire (n=54) | Paper-based questionnaire (n=74) | *P** |
|---|---|---|---|
| Male (%) | 29 (53.7%) | 35 (47.3%) | 0.59 |
| Age | 60.5 (52.3; 67.5) | 69.5 (54.5; 75.1) | < 0.05 |
| Type of ICU admission | | | |
| • Medical | 46 (85.2%) | 58 (78.4%) | 0.43 |
| • Surgical | 4 (7.4%) | 5 (6.8%) | |
| • Emergency surgery | 4 (7.4%) | 11 (14.9%) | |
| ICU length of stay | 11.8 (6.5; 20.7) | 9.6 (5.9; 16.9) | < 0.05 |
| Hospital length of stay | 21.0 (14.5; 37.5) | 22.0 (14.0; 31.0) | 0.45 |
| Mechanical ventilation days | 5.6 (4.0; 12.1) | 4.9 (3.4; 8.5) | 0.08 |
| APACHE IV score[¥] | 70.0 (56.5; 82.0) | 73.5 (60.5; 88.8) | 0.13 |
| Questionnaires | | | |
| HADS | 0 missing | 5 missing | |
| • Anxiety n (%) >= 8 | 20 (37.0%) | 17 (24.6%) | 0.14 |
| • Depression n (%) >= 8 | 15 (27.8%) | 22 (31.9%) | 0.66 |
| TSQ | 2 missing | 4 missing | |
| • n (%) >= 6 | 15 (28.8%) | 10 (14.3%) | < 0.05 |
| SF-36 | 0 missing | 8 missing | |
| • Mental Component | 48.4 (36.5; 53.6) | 47.9 (39.8; 53.8) | 0.44 |
| • Physical component | 34.6 (25.1; 42.1) | 37.6 (30.2; 44.4) | 0.21 |
| MUST | 4 missing | 22 missing | |
| • n (%) >= 1 | 27 (50.0%) | 24 (32.4%) | 0.43 |

[¥] Only calculated for the ICU survivors which met the APACHE IV inclusion criteria
*Mann-Whitney-U test for non-normally distributed data, T-test for normally distributed data, and Chi2 test for categorical data

## Discussion

We implemented a web-based triage-tool to evaluate its feasibility and to assess the outcomes of a web-based questionnaire compared to a paper-based questionnaire. In previous literature the benefits of web-based screening software has been pointed out in clinical trial settings [10]. However, our study showed that the implementation in daily practice might be difficult and we identified important barriers to consider. Survivors who responded to the web-based questionnaires were significantly younger and had a significantly longer ICU stay than those that preferred the paper-based questionnaires. Health status at the time of filing out the questionnaire did not differ between the two groups. Strikingly, the prevalence of mental,

physical and nutritional problems was equally high in both groups and the majority did not receive care for these complaints before they visited the post-ICU clinic.

Though the tool was evaluated and adjusted before implementation, eight (57.1%) caregivers found the software too complex to use. The average SUS score was 56, indicating a less than average usability and necessitating improvement of the software.

Over 40% of the respondents used the web-based questionnaire. Caregivers stated that many survivors did not have an e-mail address and expressed that survivors in general are not ready yet to use the web-based questionnaires because of their age. This was not in line with the results of the telephone calls where only one (3.6%) survivor stated that he did not had an e-mail address. Moreover, as our society is focussing and relying more and more on digital systems, survivors not having an e-mail address will be no barrier in the future. Already in 2013, 95% of all Dutch households had access to a computer with an internet connection [19].

Digitally-issued questionnaires have major benefits compared to paper-based questionnaires, such as more complete data, less entry errors and easy storage of data [8]. Our study confirmed this finding as we found that in the paper-based questionnaire group, there was more information missing. A possible explanation can be the use of checks and prompts in the web-based questionnaires when items were not filled-out. Another major benefit is that by using web-based screening software survivors with possible health problems can be identified without visiting the hospital. The outcomes of the questionnaires can be used in clinical decision making and tailored care. This will improve the effectiveness of the treatments.

The prevalence of possible mental, physical and nutritional problems was high among the respondents. However, not all survivors received the appropriate care after hospital discharge. Even though there is no consensus on the (cost-) effectiveness of intensive care follow-up programmes [20-22], we believe that our triage-tool is a step in the right direction. Follow-up care should be offered as stepped-care, so it can be tailored to the needs of survivors. The triage-tool makes it possible to highlight the problem areas so they can be addressed during consultation. Furthermore, the triage-tool can be used to reach large groups of survivors as the data collection and processing is less labour intensive.

Patients choosing to fill out questionnaires online are significantly younger and reported a better psychological health compared to those preferring paper-based questionnaires [23]. In our study survivors who used the web-based questionnaires were also younger. However, the psychological health seemed to be better in the paper-based group, although not significantly. According to Baldwin et al [24], younger age and prolonged hospital stay are associated with lower mental or physical quality of life. Survivors which used the web-based questionnaires had a significant longer ICU stay, and this can be a possible explanation for the conflicting results.

A strength of this study was the use of mixed methods, i.e. qualitative and quantitative methods. By using mixed methods we were able to verify the statements of caregivers with the clinical data and questionnaire outcomes of survivors. For example, caregivers stated that a large part of survivors did not have an e-mail address and that survivors were sometimes not able to fill out questionnaires due to their health-status. However, these believes were not validated with the phone calls. A possible explanation can be that survivors that could not been reached had the worst health status [25].

Though 531 survivors were eligible for follow-up care, only 221 received an invitation to fill in the questionnaire and visit the follow-up clinic. A limitation of this study is that we have little information on why certain survivors were, and others were not, invited. The caregivers mentioned the absence of financial support from the department as a major problem. Some caregivers provide follow-up care in their own time, this makes it difficult to offer ICU follow-up care customarily.

During the interviews, all caregivers repeatedly stressed the importance of follow-up care for survivors, to address the burden these survivors suffer after their ICU admission. They all endorse the necessity and the benefits of ICU follow-up care, however these ideas are not yet supported by scientific research. Filling out web-based questionnaires will have added value due to our digitalizing society. Questionnaire outcomes are present during consultation and can be discussed with survivors and their families. The results of these web-bases questionnaires can be used to gain insight in the efficiency of the ICU follow-up care, if stored in a national database with options to benchmark the long-term outcomes of survivors.

## Conclusions

Web-based screening software has major benefits compared to paper-based screening however the implementation has shown to be difficult and there are important barriers to consider. In order to successfully implement a new web-based triage-tool, caregivers need time and support to use it. E-mail addresses of survivors should be queried at hospital admission so that it won't be necessary to collect the e-mail address after hospital discharge. In both web-based and paper-based population there was a large prevalence of survivors with possible mental, physical and nutritional problems and we suggest ICU follow-up care in order to address these problems. We think that our software is a starting point of making ICU follow-up care feasible and effective.

## References

1. Angus DC, Carlet J. Surviving intensive care: a report from the 2002 Brussels Roundtable. Intensive Care Med. 2003;29:3.
2. Oeyen SG, Vandijck DM, Benoit DD, Annemans L, Decruyenaere JM. Quality of life after intensive care: a systematic review of the literature. Crit Care Med. 2010;38:12.
3. Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. Crit Care Med. 2012;40:2.
4. van der Schaaf M, Beelen A, Dongelmans DA, Vroom MB, Nollet F. Functional status after intensive care: a challenge for rehabilitation professionals to improve outcome. J Rehabil Med. 2009;41:5.
5. Tan T, Brett SJ, Stokes T, Guideline Development G. Rehabilitation after critical illness: summary of NICE guidance. BMJ. 2009;338.
6. Korkeila K, Suominen S, Ahvenainen J, Ojanlatva A, Rautava P, Helenius H et al. Non-response and related factors in a nation-wide health survey. Eur J Epidemiol. 2001;17:11.
7. van der Schaaf M, Beelen A, Dongelmans DA, Vroom MB, Nollet F. Poor functional recovery after a critical illness: a longitudinal study. J Rehabil Med. 2009;41:13.
8. van Gelder MM, Bretveld RW, Roeleveld N. Web-based questionnaires: the future in epidemiology? Am J Epidemiol. 2010;172:11.
9. Coons SJ, Eremenco S, Lundy JJ, O'Donohoe P, O'Gorman H, Malizia W. Capturing Patient-Reported Outcome (PRO) Data Electronically: The Past, Present, and Promise of ePRO Measurement in Clinical Trials. Patient. 2015;8:4.
10. Cox CE, Wysham NG, Kamal AH, Jones DM, Cass B, Tobin M et al. Usability Testing of an Electronic Patient-Reported Outcome System for Survivors of Critical Illness. Am J Crit Care. 2016;25:4.
11. van der Schaaf M, Bakhshi-Raiez F, Van der Steen M, Dongelmans DA, De Keizer NF. Recommendations for the organization of intensive care follow-up clinics; report from a survey and conference of Dutch intensive cares. Minerva Anestesiol. 2015;81:2.
12. van de Klundert N, Holman R, Dongelmans DA, de Keizer NF. Data Resource Profile: the Dutch National Intensive Care Evaluation (NICE) Registry of Admissions to Adult Intensive Care Units. Int J Epidemiol. 2015;44:6.
13. Dutch National Intensive Care Evaluation (NICE) registry http://www.stichting-nice.nl Accessed 08.11.2016.

14. Mahieu GR. Follow-up system for intensive care patients: Preliminary evaluation of workflow and usability. Amsterdam: University of Amsterdam; 2014.
15. Boren MT, Ramey J. Thinking aloud: Reconciling theory and practice. Ieee Transactions on Professional Communication. 2000;43:3.
16. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nurs Health Sci. 2013;15:3.
17. Brooke J. SUS: A Quick and Dirty Usability Scale. In: Usability Evaluation in Industry. London: Taylor & Francis; 1996. p. 189–94.
18. IBM Corp. IBM SPSS Statistics for Windows. Version 24.0. Armonk, NY. IBM Corp.
19. Centraal Bureau voor de Statistiek (CBS). In: Statline. . http://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=71102ned&D1=0-3,30-34&D2=0-10&D3=0,l&HDR=G2,T&STB=G1&VW=T. Accessed 01.02.2017.
20. Cuthbertson BH, Rattray J, Campbell MK, Gager M, Roughton S, Smith A et al. The PRaCTICaL study of nurse led, intensive care follow-up programmes for improving long term outcomes from critical illness: a pragmatic randomised controlled trial. BMJ. 2009;339.
21. Jones C, Skirrow P, Griffiths RD, Humphris GH, Ingleby S, Eddleston J et al. Rehabilitation after critical illness: a randomized, controlled trial. Crit Care Med. 2003;31:10.
22. Elliott D, McKinley S, Alison J, Aitken LM, King M, Leslie GD et al. Health-related quality of life and physical recovery after a critical illness: a multi-centre randomised controlled trial of a home-based physical rehabilitation program. Crit Care. 2011;15:3.
23. Zuidgeest M, Hendriks M, Koopman L, Spreeuwenberg P, Rademakers J. A comparison of a postal survey and mixed-mode survey using a questionnaire on patients' experiences with breast care. J Med Internet Res. 2011;13:3.
24. Baldwin FJ, Hinge D, Dorsett J, Boyd OF. Quality of life and persisting symptoms in intensive care unit survivors: implications for care after discharge. BMC Res Notes. 2009;2.
25. Unroe M, Kahn JM, Carson SS, Govert JA, Martinu T, Sathy SJ et al. One-year trajectories of care and resource utilization for recipients of prolonged mechanical ventilation: a cohort study. Ann Intern Med. 2010;153:3.

## Ethics

The NICE registry is registered according to the Dutch Personal Data Protection Act. The need for ethical approval for this study was waived by the Medical Ethics Committee of the Academic Medical Center and stored under number W17-354.

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## Author's contribution

IvB gave the training to use the triage-tool, conducted all semi-structured interviews with the caregivers, transcribed the interviews verbatim, coded the interviews and drafted the manuscript.

FBR gave the training to use the triage-tool, coded the interviews and helped to draft the manuscript.

NdK participated in the design and coordination of this study.

DAD helped in analysing and interpreting the results.

MvdS participated in the design and coordination of this study.

All authors discussed the themes and statements of the coding, read and approved the final manuscript.

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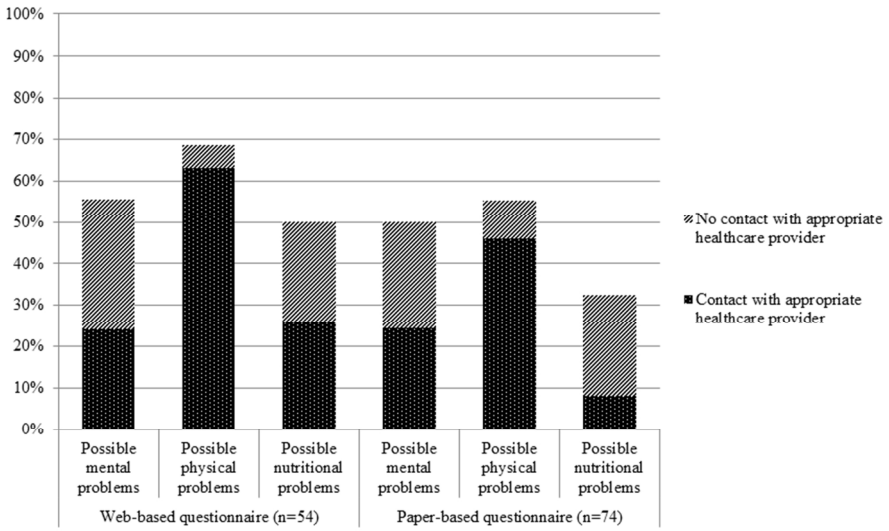
Figure 1. Prevalence of mental problems, physical problems and nutritional problems

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**Work-related questions**

1. Describe the job you had before your ICU admission
2. Which situation reflects your situation best: before my ICU admission I was/I had:
    a. employed
    b. self-employed
    c. partially incapacitated
    d. (early) retired
    e. unemployed / looking for employment
    f. fully incapacitated
    g. social assistance
    h. fulltime ‘man around the house'/’woman around the house’
    i. student
3. What were your main tasks in the job you had before your ICU admission?
    a. mostly physically demanding tasks
    b. mostly mentally demanding tasks
    c. a mixture of physically and mentally demanding tasks
    d. no physically or mentally demanding tasks
4. According to you contract, how many hours did you work before your ICU admission?
5. How many hours did you work before your ICU admission?
6. Describe your current job
7. Which situation reflects your current situation best: after my ICU admission I was/I had:
    a. employed
    b. self-employed

c. partially incapacitated

d. (early) retired

e. unemployed / looking for employment

f. fully incapacitated

g. social assistance

h. fulltime ‘man around the house'/’woman around the house’

i. student

8. What are your main tasks in your current job?

a. mostly physically demanding tasks

b. mostly mentally demanding tasks

c. a mixture of physically and mentally demanding tasks

d. no physically or mentally demanding tasks

9. According to your current contract, how many hours do you work?

10. How many hours do you work after your ICU admission?

11. Are you disturbed by your health status within your current job?

a. no

b. a bit

c. strongly

12. Did your financial situation decline compared to the situation before your ICU admission?

**Common problems after an ICU admission**

| | | |
|---|---|---|
| Do you experience decreased vision compared to the situation before ICU admission? | Yes | No |
| Do you experience decreased hearing compared to the situation before ICU admission? | Yes | No |
| Do you experience decreased taste compared to the situation before ICU admission? | Yes | No |
| Do you experience decreased voice compared to the situation before ICU admission? | Yes | No |
| Do you have more problems with your balance compared to your situation before ICU admission | Yes | No |
| Do you experience a change in defecation (consistency, frequency) compared to your situation before ICU admission? | Yes | No |
| Do you experience more problems urinating compared to the situation before ICU admission? | Yes | No |

| | | |
|---|---|---|
| Do you experience decreased sexual functions compared to the situation before ICU admission? | Yes | No |
| Do you experience a change menstruation compared to the situation before ICU admission? | Yes | No |
| Do you experience more stiffness of your joints compared to the situation before ICU admission? | Yes | No |
| Do you experience more muscle weakness compared to the situation before ICU admission? | Yes | No |
| Do you experience more hair loss compared to the situation before ICU admission? | Yes | No |
| Do you experience more itching or exfoliation of your skin compared to the situation before ICU admission? | Yes | No |

**Visits to healthcare professionals after ICU admission**

| | | |
|---|---|---|
| Did you visit a general practitioner within the last 3 months? | Yes | No |
| Did you visit a district nurse or did you receive professional home care within the last 3 months? | Yes | No |
| Did you visit a physical therapist within the last 3 months? | Yes | No |
| Did you visit an occupational therapist within the last 3 months? | Yes | No |
| Did you visit a speech therapist within the last 3 months? | Yes | No |
| Did you visit a dietician within the last 3 months? | Yes | No |
| Did you visit a social worker within the last 3 months? | Yes | No |
| Did you visit a psychologist within the last 3 months? | Yes | No |
| Did you visit a psychiatrist within the last 3 months? | Yes | No |
| Did you visit a rehabilitation specialist within the last 3 months? | Yes | No |
| Did you visit a pulmonologist within the last 3 months? | Yes | No |

| | | |
|---|---|---|
| Did you visit a dermatologist within the last 3 months? | Yes | No |
| Did you visit a neurologist within the last 3 months? | Yes | No |
| Did you visit an orthopaedist within the last 3 months? | Yes | No |
| Did you visit another healthcare professional within the last 3 months? If yes, which healthcare professional? | | |

# Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No. Item | Guide questions/description | Reported on Page # |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| 1. Inter viewer/facilitator | Which author/s conducted the inter view or focus group? | 8 |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | 1 |
| 3. Occupation | What was their occupation at the time of the study? | 8 |
| 4. Gender | Was the researcher male or female? | - |
| 5. Experience and training | What experience or training did the researcher have? | - |
| *Relationship with participants* | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | 5 |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 5-8 |
| 8. Interviewer characteristics | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | - |
| **Domain 2: study design** | | |
| *Theoretical framework* | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 8 |
| *Participant selection* | | |
| 10. Sampling | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 5-8 |
| 11. Method of approach | How were participants approached? e.g. face-to-face, telephone, mail, email | 5-8 |
| 12. Sample size | How many participants were in the study? | 9 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | - |
| *Setting* | | |
| 14. Setting of data collection | Where was the data collected? e.g. home, clinic, workplace | 8 |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | - |
| 16. Description of sample | What are the important characteristics of the | 9 |

| | | |
|---|---|---|
| | sample? e.g. demographic data, date | |
| *Data collection* | | |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | N/A |
| 18. Repeat interviews | Were repeat inter views carried out? If yes, how many? | N/A |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | 8 |
| 20. Field notes | Were field notes made during and/or after the inter view or focus group? | - |
| 21. Duration | What was the duration of the inter views or focus group? | 9 |
| 22. Data saturation | Was data saturation discussed? | - |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | N/A |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| 24. Number of data coders | How many data coders coded the data? | 8 |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | N/A |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | 8 |
| 27. Software | What software, if applicable, was used to manage the data? | Word |
| 28. Participant checking | Did participants provide feedback on the findings? | 9-11 |
| *Reporting* | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | Table 3 |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | 12-14 |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | 9-11 |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | 12-14 |

**STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology***

**Checklist for cohort, case-control, and cross-sectional studies (combined)**

| Section/Topic | Item # | Recommendation | Reported on page # |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | 1 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | 2 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 4 |
| Objectives | 3 | State specific objectives, including any pre-specified hypotheses | 4 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | 5-8 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 5-8 |
| Participants | 6 | (*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up<br>*Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls<br>*Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants | 5<br>Table 1 |
| | | (*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed<br>*Case-control study*—For matched studies, give matching criteria and the number of controls per case | |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 6-8<br>Table 2 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | 6-8 |
| Bias | 9 | Describe any efforts to address potential sources of bias | |
| Study size | 10 | Explain how the study size was arrived at | 5-8 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | 6-7<br>Table 2 |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | 8 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | - |
| | | (*c*) Explain how missing data were addressed | - |
| | | (*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed<br>*Case-control study*—If applicable, explain how matching of cases and controls was addressed | - |

| | | | |
|---|---|---|---|
| | | *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy | |
| | | (*e*) Describe any sensitivity analyses | - |
| **Results** | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 9-12 |
| | | (b) Give reasons for non-participation at each stage | 9-12 |
| | | (c) Consider use of a flow diagram | - |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | Table 4 |
| | | (b) Indicate number of participants with missing data for each variable of interest | Table 4 |
| | | (c) *Cohort study*—Summarise follow-up time (eg, average and total amount) | |
| Outcome data | 15* | *Cohort study*—Report numbers of outcome events or summary measures over time | |
| | | *Case-control study*—Report numbers in each exposure category, or summary measures of exposure | |
| | | *Cross-sectional study*—Report numbers of outcome events or summary measures | 9-12<br>Table 4 |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 9-12 |
| | | (*b*) Report category boundaries when continuous variables were categorized | Table 2 |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | - |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | - |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | 12-13 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 14 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 12-14 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 12-14 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 3 |

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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# Lessons learned during the implementation of a web-based triage-tool for Dutch intensive care follow-up clinics



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| | |

# Lessons learned during the implementation of a web-based triage-tool for Dutch intensive care follow-up clinics

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**Abstract**

**Objectives:** Screening for symptoms of Post Intensive Care Syndrome is based on a long list of questionnaires, filled out by the ICU survivor and manually reviewed by the health professional. This is an inefficient and time consuming process. The aim of this study was to evaluate the feasibility of a web-based triage-tool and to compare the outcomes from web-based questionnaires to those from paper-based questionnaires.

**Design:** A mixed methods study.

**Setting**: Nine Dutch ICU follow-up clinics.

**Participants:** 221 ICU survivors and 14 health professionals.

**Interventions:** A web-based triage-tool was implemented by nine ICU follow-up clinics. End-users, i.e. health professionals, were interviewed in order to evaluate the feasibility of the triage-tool. ICU survivors were invited to fill out web-based questionnaires 3 months after hospital discharge.

**Primary outcomes:** Outcomes of the questionnaires were merged with clinical data from a national quality registry to assess the differences in outcomes between paper-based and web-based questionnaires.

**Results:** 221 ICU survivors received an invitation to fill out questionnaires, 93 (42.1%) survivors did not respond to the invitation. Respondents to the web-based questionnaires (n=54) were significantly younger and had a significantly longer ICU stay than those who preferred the paper-based questionnaires (n=74). The prevalence of mental, physical and nutritional problems was high, although comparable between the groups. Health professionals' interviews revealed that the software was complex to use (n=8) and although e-mailing survivors is very convenient, not all survivors have an e-mail address (n=7).

**Conclusions:** Web-based screening software has major benefits compared to paper-based screening. However, implementation has shown to be rather difficult and there are important barriers to consider. Although different in age, the health status is comparable between the users of the web-based questionnaire and paper-based questionnaire.

Key words: web-based questionnaires, triage, intensive care, survivors, PICS, mixed methods

**Strengths and limitations of this study**

- A strength of this study is that we implemented the web-based triage-tool in a clinical care setting instead of a clinical trial setting.
- Outcomes and characteristics of patients which preferred the web-based questionnaires were compared with the outcomes and characteristics of patients which preferred the paper-based questionnaires.
- By using mixed methods we were able to verify the statements of health professionals with the clinical data and questionnaire outcomes.

**Funding and competing interests statement**

All the authors have declared no conflicts of interest and this research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors. None of the material from this study is included in another manuscript, has been published previously, is currently under consideration for publication elsewhere, nor has been posted on the internet.

## Introduction

Intensive Care Unit (ICU) survivors frequently suffer long-term and severe complaints after ICU discharge [1, 2] and a single term is used to identify the presence of one or more impairments after critical illness: Post Intensive Care Syndrome (PICS) [3].

Because of the complexity and magnitude of the complaints, multidisciplinary care after ICU discharge is required [4]. ICU follow-up care aims to detect PICS in an early stage and the ICU survivors will be referred to the appropriate health professional(s) during consultation. In some ICU guidelines it is recommended to have an ICU follow-up clinic [5].

Generally, screening for symptoms of PICS is based on a long list of paper-based questionnaires, filled out manually by the survivor and reviewed by the health professional before or during consultation. This is an inefficient and time consuming process. Moreover, there is a high rate of non-responders due to the age and medical conditions of survivors and because survivors cannot always be traced on their home address [6, 7].

We created a web-based triage-tool to collect patient-reported screening data. The tool supports automatic processing of the data before presenting it to the health professional. Web-based screening has major benefits compared to paper-based screening, for example more complete data, less entry errors and easy storage of data [8], leading to enhanced integrity and accuracy of outcome data [9]. In previous literature the benefits of web-based screening software has been pointed out in clinical trial settings [10]. However, research on the implementation of software in clinical care and the use of web-based screening in ICU survivors and ICU personnel is scarce.

The aim of this study was to evaluate the feasibility of our web-based triage-tool in the ICU follow-up clinic and to assess the outcomes gained by a web-based questionnaire compared to those from conventional paper-based questionnaires.

## Materials and methods

*Setting*

Based on the recommendations of Van der Schaaf et al. [11] (table 1), a new web-based triage-tool was created and tested during a pilot-study. The tool supports automatic collection and processing of data for ICU follow-up care. The study was conducted between the 1st of June 2014 and the 30th of June 2015. All ICUs participating in the Dutch National Intensive Care Evaluation (NICE) registry that had an ICU follow-up clinic were invited to participate in this pilot-study. The NICE registry is a quality registry which contains demographic data, physiological data and clinical data for all ICU patients in the Netherlands [12, 13]. We aimed to include 10 ICU's in this pilot study.

**Table 1.** Recommendations for eligibility of ICU survivors for ICU follow-up clinics [11]

- Invite all survivors who received > 48 h mechanical ventilation
- Invite the partners of survivors
- Plan the first visit to the ICU follow-up clinic 12 weeks after hospital discharge with the possibility for a follow-up at indication
- Screen survivors with respect to their needs and ICU related sequelae
- Use electronic patient-reported screening instruments to identify survivors in the need for ICU follow-up care
- Have an ICU nurse, whether or not with an intensivist, carrying out the ICU follow-up clinic
- Involve a physiotherapist to perform a comprehensive physical screening
- Integrate follow-up care data into a national quality registry for ICU to monitor and improve quality of life and functional status of survivors

*Web-based triage-tool*

The triage-tool includes a module for health professionals to be used in the follow-up clinics and a web-based questionnaire module for ICU survivors.

During the development of the triage-tool, both modules were tested for usability. The module for health professionals was evaluated with four health professionals by means of semi-structured interviews [14]. The usability of the web-based questionnaire module was evaluated with four ICU survivors using the Think Aloud method [14, 15]. Outcomes of the semi-structured interviews and the Think Aloud sessions resulted in minor adjustments of the triage-tool prior to implementation of the triage-tool in the pilot-study [14].

The triage-tool automatically extracted data of eligible survivors from the hospital information system (HIS). Nine weeks after hospital discharge, the health professionals received a prompt to send the survivor an invitation by e-mail to fill out a set of online questionnaires and to invite the survivor to visit the ICU follow-up clinic 3 months after hospital discharge. If there was no response from the survivor within the next week, the health professional received a prompt to call the survivor. During this phone call, the health professional would ask for the reason of the non-response and explain the importance of screening for PICS and a visit to the ICU follow-up clinic. If survivors stated that they were unable to fill out the online questionnaire, a paper-based questionnaire was issued. The paper-based questionnaires were entered in the system manually by the health professional or the secretary.

The pilot-study included the questionnaires described in table 2. Besides these validated questionnaires, work and income related questions, common problems after ICU admission and visits to health professionals after ICU admission were queried (appendix 1).

**Table 2.** Validated questionnaires used during this study

| Name | Description | Cut-off point |
|---|---|---|
| Hospital Anxiety and Depression Scale (HADS) [16] | A 14-items screening tool consisting of two subscales which evaluate symptoms of depression (seven items) and symptoms of anxiety (seven items) | Score of >= 8 to identify patients prone to develop depression or anxiety |
| Short From 36 (SF-36) [17] | A 36-item screening-tool comprising two components; a physical- and a mental component score. Component scores range from 0 to 100, with higher scores indicating better health status [18] | Score of < 40 to identify decreased physical or mental health component |
| Trauma Screening Questionnaire (TSQ) [19] | A 10-item screening tool used to identify post-traumatic stress disorder (PTSD) | Score of >= 6 to identify possible PTSD |
| Malnutrition Universal Screening Tool (MUST) [20] | A 3-item screening tool to obtain the risk of malnutrition | Scores >= 1 to identify patients with a risk of malnutrition |

The results of the questionnaires were automatically processed by the triage-tool and compared to the cut-off points. During the follow-up consultation the health professional and the survivor discussed the outcomes of the questionnaire and the survivor was referred to a specialist if necessary. This was similar to the process before the implementation of the triage-tool except for the fact that the outcomes of the questionnaires were calculated and present before the start of the consultation.

Health professionals were trained to use the software before the start of the study. The 3-hour training was given by the developers of the tool and a researcher (IvB or FBR). During the pilot-study, the health professionals were contacted regularly and offered assistance when necessary.

*Evaluation of the feasibility of the triage-tool*

After finishing the pilot-study, semi-structured interviews were conducted with health professionals who used the tool, to gain insight in the feasibility of the triage-tool. The semi-structured interviews were hold from July 2015 until September 2015 and conducted by one researcher (IvB). All health professionals were interviewed in their own working environment and an informed consent was verbally issued and recorded before the interview started.

All interviews were recorded digitally and transcribed verbatim. The Thematic Content Analysis (TCA) method was used to analyse the qualitative data [21]. All interviews were coded individually by two researches (IvB and FBR). Both researchers extracted the statements from the transcripts and grouped the statements by themes. The themes and statements were discussed until 100% agreement was achieved on the coding.

The statements of the health professionals were compared with the characteristics of the survivors and the outcomes of the questionnaires in order to relate the qualitative data to the quantitative data.

Finally, the health professionals were requested to fill out the System Usability Scale (SUS) [22]. The SUS is a tool to evaluate software tools. Scores range from 0-100 and a SUS score above 68 indicating above average usability [22].

*Questionnaire outcomes of the ICU survivors*

The outcomes of the questionnaires were used to evaluate the type and severity of symptoms of PICS present in survivors. The anonymised data of the questionnaires were linked with clinical data from the NICE registry to gain insight in the demographics and clinical differences between survivors who filled out the web-based questionnaires compared to those who filled out the paper-based questionnaires. Data-linking was based on a unique identifying number available in both databases.

Categorical data was presented as numbers and percentages, continuous data as medians and interquartile ranges (IQR). Differences between the web-based questionnaire group and the paper-based questionnaire group for non-normally distributed data were calculated using the Mann-Whitney-U test. Differences between the two groups for normally distributed data were calculated using the T-test. For categorical data, the $Chi^2$ test was used to assess the

differences between the study groups. All analyses were performed using IBM SPSS Statistics version 24 [23].

**Patient and Public Involvement**

No patients were directly involved in the development of the research question, design of the study or interpretation of the results. However, the usability of the web-based questionnaire module was evaluated with ICU survivors. Outcomes of the evaluation resulted in minor adjustments of the module prior to the implementation of the triage-tool in this pilot-study.

**Results**

Of the 23 Dutch ICUs with an ICU follow-up clinic, nine ICUs (39.1%) participated in the pilot- study. One ICU withdrew due to reorganisation 8 months after the start of the study. Of the eight participating ICUs, 1 (12.5%) was located in an university hospital, 1 (12.5%) in a teaching hospital and 6 (75.0%) in community hospitals.

*Evaluation of the feasibility of the triage-tool*

During this pilot-study, 531 survivors were eligible for follow-up care and were extracted from the HIS. Before sending out the invitations, the health professional would check if the survivor was still alive and 42 (7.9%) survivors were reported as 'deceased after hospital discharge'. Of the remaining survivors, 221 (45.2%) received an invitation to fill out the questionnaires and to attend follow-up care. Other reasons for not inviting the survivor, beside death, were not collected. There were no significant differences in characteristics between survivors who were invited or not.

Ninety-three (42.1%) survivors did not respond to the invitation. Of the non-responders, 28 (30.1%) were phoned by the health professional to ask for the reason for non-response; three (10.7%) could not be reached on their phone number, eight (28.6%) said they were well and did not need follow-up care, three (10.7%) said they were unable to fill out questionnaires and to attend follow-up care due to their poor health status, two (7.1%) had no recollection of the IC admission, six (21.4%) were already involved in a rehabilitation program, one (3.6%) had no computer, and five (17.9%) gave other reasons. It is unknown whether the other 65 non-responders were not contacted or that the phone calls were not registered. There were no significant differences in characteristics between non-responders and responders.

Fourteen health professionals worked with the system and were interviewed; five intensivists, six ICU nurses, one physical therapist and two medical secretaries. The duration of the interviews ranged from 21 minutes to 39 minutes. Ten health professionals filled out the SUS with an average score of 56.

Table 3 shows the main barriers to using the tool for survivors, according to the health professionals. E-mail addresses of survivors or family members were not always routinely collected before the start of the study. During the study, this was implemented in the regular workflow in the HIS.

Health professionals were surprised to find out that a large part of survivors mentioned not to have an e-mail address, even the 'younger' survivors of forty to fifty years old. Over 70% of the health professionals said that the ICU population in general is older, and that survivors are not ready to use the web-based questionnaires because of their age, that survivors were too sick to fill out the questionnaires or that survivors did not want to be confronted with the ICU admission.

According to the health professionals, if follow-up care is offered on a voluntary basis, some survivors will reject it (28.6%). Lack of interest, avoidance as part of PTSD, distance to hospital, burden to ask health professionals for support are frequently stated reasons by the health professionals for survivors to reject ICU follow-up care. Most health professionals (85.7%) would like to see follow-up care as part of the routine care, only few health professionals think of the follow-up care as an extra service to the survivor.

**Table 3.** Themes exemplifying the statements of the 14 health professionals

| Themes | Statements |
|---|---|
| Personal themes | E-mailing the patient is very convenient, especially during night shifts (n=7).<br>I did not think about e-mailing the patient, I like to call patients (n=2). |
| Software related themes | The software was complex (n=8).<br>Patients' e-mail addresses were not available in the HIS at the start of the pilot, calling the patient to collect the e-mail address was very time consuming (n=8).<br>Since we used so little, I forgot how to send an e-mail with it (n=5). |
| Patient related themes | Patients did not have an e-mail address, even not the patients of 40 to 50 years old (n=10).<br>Patients are not ready to use the web-based questionnaires, in 10 years this will be different (n=10).<br>Some patients are not interested in follow-up care, sometimes they are too sick and sometimes they already have support (n=10). |
| Organization related themes | There are no resources available for follow-up care, we arranged it in our own time (n=4)<br>A follow-up consultation is not part of the 'routine care process', patients perceive it as optional and might not come (n=4). |

*Questionnaire outcomes of the ICU survivors*

In total 54 survivors filled out the web-based questionnaires and 74 survivors used the paper-based version. Eighty-seven survivors attended ICU follow-up care. Table 4 gives an overview of characteristics of survivors, grouped by paper-based or web-based data-collection. Survivors who preferred web-based questionnaires were significantly younger compared to survivors who filled out the paper-based questionnaires ($p< 0.05$), and had a longer ICU stay ($p< 0.05$). Survivors that filled out the web-bases questionnaires had a significant higher prevalence of PTSD, measured with the TSQ. For all other patient-reported outcomes, there were no significant differences between survivors which filled out the web-based questionnaires as opposed to survivors who filled out paper-based questionnaires.

In the paper-based group, less questionnaire outcomes could be calculated due to missing items, i.e. in the paper-based group 13.2% of the results were missing, in the web-based questionnaire group this was 2.8%.

Within both questionnaire groups there was a large prevalence of possible mental problems, physical problems and nutritional problems (table 4 and figure 1). Not all survivors with possible problems had contact with the appropriate healthcare professionals during the time of filling out the questionnaires.

**Table 4.** Characteristics of ICU survivors who returned the questionnaires

| | Web-based questionnaire (n=54) | Paper-based questionnaire (n=74) | *P** |
|---|---|---|---|
| Male (%) | 29 (53.7%) | 35 (47.3%) | 0.59 |
| Age | 60.5 (52.3; 67.5) | 69.5 (54.5; 75.1) | < 0.05 |
| Type of ICU admission | | | |
| • Medical | 46 (85.2%) | 58 (78.4%) | 0.43 |
| • Surgical | 4 (7.4%) | 5 (6.8%) | |
| • Emergency surgery | 4 (7.4%) | 11 (14.9%) | |
| ICU length of stay | 11.8 (6.5; 20.7) | 9.6 (5.9; 16.9) | < 0.05 |
| Hospital length of stay | 21.0 (14.5; 37.5) | 22.0 (14.0; 31.0) | 0.45 |
| Mechanical ventilation days | 5.6 (4.0; 12.1) | 4.9 (3.4; 8.5) | 0.08 |
| APACHE IV score[¥] | 70.0 (56.5; 82.0) | 73.5 (60.5; 88.8) | 0.13 |
| Questionnaires | | | |
| HADS | 0 missing | 5 missing | |
| • Anxiety n (%) >= 8 | 20 (37.0%) | 17 (24.6%) | 0.14 |
| • Depression n (%) >= 8 | 15 (27.8%) | 22 (31.9%) | 0.66 |
| TSQ | 2 missing | 4 missing | |
| • n (%) >= 6 | 15 (28.8%) | 10 (14.3%) | < 0.05 |
| SF-36 | 0 missing | 8 missing | |
| • Mental Component | 48.4 (36.5; 53.6) | 47.9 (39.8; 53.8) | 0.44 |
| • Physical component | 34.6 (25.1; 42.1) | 37.6 (30.2; 44.4) | 0.21 |
| MUST | 4 missing | 22 missing | |
| • n (%) >= 1 | 27 (50.0%) | 24 (32.4%) | 0.43 |

[¥] Only calculated for the ICU survivors which met the APACHE IV inclusion criteria

*Mann-Whitney-U test for non-normally distributed data, T-test for normally distributed data, and Chi2 test for categorical data

**Discussion**

We implemented a web-based triage-tool to evaluate its feasibility and to assess the outcomes of a web-based questionnaire compared to a paper-based questionnaire. In previous literature the benefits of web-based screening software has been pointed out in clinical trial settings [10]. However, our study showed that the implementation in daily practice might be difficult and we identified important barriers to consider. Survivors who responded to the web-based questionnaires were significantly younger and had a significantly longer ICU stay than those that preferred the paper-based questionnaires. Health status at the time of filing out the questionnaire did not differ between the two groups. Strikingly, the prevalence of mental, physical and nutritional problems was equally high in both groups and the majority did not receive care for these complaints before they visited the ICU follow-up clinic.

Though the tool was evaluated and adjusted before implementation, eight (57.1%) health professionals found the software too complex to use. The average SUS score was 56, indicating a less than average usability and necessitating improvement of the software. A point of interest is the time between the training and te start of the pilot study. Not all ICU follow-up clinics started the pilot study at te same time, while the training was given on three dates during two consecutive weeks. Moreover, during the evaluation the pilot study, five healthcare professionals mentioned that they used the software so little, they forgot how to send an e-mail with it. For future research it advised to plan the training shortly before the start of the study and to use the new software on a regular basis.

Over 40% of the respondents used the web-based questionnaire. Health professionals stated that many survivors did not have an e-mail address and expressed that survivors in general are not ready yet to use the web-based questionnaires because of their age. This was not in line with the results of the telephone calls where only one (3.6%) survivor stated that he did not had an e-mail address. Moreover, as our society is focussing and relying more and more on digital systems, survivors not having an e-mail address will be no barrier in the future. Already in 2013, 95% of all Dutch households had access to a computer with an internet connection [24].

Digitally-issued questionnaires have major benefits compared to paper-based questionnaires, such as more complete data, less entry errors and easy storage of data [8]. Our study confirmed this finding as we found that in the paper-based questionnaire group, there was

more information missing. A possible explanation can be the use of checks and prompts in the web-based questionnaires when items were not filled-out. Another major benefit is that by using web-based screening software survivors with possible health problems can be identified without visiting the hospital. The outcomes of the questionnaires can be used in clinical decision making and tailored care. This will improve the effectiveness of the treatments.

The prevalence of possible mental, physical and nutritional problems was high among the respondents. However, not all survivors received the appropriate care after hospital discharge. Even though there is no consensus on the (cost-) effectiveness of intensive care follow-up programmes [25-27], we believe that our triage-tool is a step in the right direction. Follow-up care should be offered as stepped-care, so it can be tailored to the needs of survivors. The triage-tool makes it possible to highlight the problem areas so they can be addressed during consultation. Furthermore, the triage-tool can be used to reach large groups of survivors as the data collection and processing is less labour intensive.

People choosing to fill out questionnaires online were significantly younger compared to those preferring paper-based questionnaires [28]. According to previous published studies younger age has been found to be a risk factor for PTSD [29] and a prolonged hospital stay is associated with lower mental or physical quality of life [30]. In our study survivors who used the web-based questionnaires were also younger compared to survivors in the paper-based group, and had a longer ICU stay. This can be a possible explanation for the finding that survivors in the web-based questionnaire group had a significantly higher risk of developing PTSD compared to survivors in the paper-based group.

A strength of this study was the use of mixed methods, i.e. qualitative and quantitative methods. By using mixed methods we were able to verify the statements of health professionals with the clinical data and questionnaire outcomes of survivors. For example, health professionals stated that a large part of survivors did not have an e-mail address and that survivors were sometimes not able to fill out questionnaires due to their health-status. However, these concerns were not validated with the phone calls. A possible explanation can be that survivors that could not been reached had the worst health status [31].

Though 531 survivors were eligible for follow-up care, eventually only 128 survivors responded to the questionnaires. This is firstly due to the fact that only 221 of the 531 eligible survivors received an invitation to fill in the questionnaire and visit the follow-up clinic. A limitation of this study is that we have little information on why certain survivors were, and others were not, invited. During the interviews the health professionals mentioned the absence of financial support from the department as a major problem. Some health professionals provide follow-up care in their own time, this makes it difficult to offer ICU follow-up care customarily. Secondly, of the 221 ICU survivors invited to fill out the questionnaires, 93 did not respond resulting in a response rate of 57.9%. A review conducted on the quality of life after ICU admission described that three (6%) of their included studies had a response rate of < 50% and 24 studies (45%) had a response rate between 50% and 79% [2]. In sight of this review, we consider the response rate of our study average.

During the interviews, all health professionals repeatedly stressed the importance of follow-up care for survivors, to address the burden these survivors suffer after their ICU admission. They all endorse the necessity and the benefits of ICU follow-up care, however these ideas are not yet supported by scientific research. Filling out web-based questionnaires will have added value due to digitalizing society. Questionnaire outcomes are present during consultation and can be discussed with survivors and their families. The results of these web-bases questionnaires can be used to gain insight in the efficiency of the ICU follow-up care, if stored in a national database with options to benchmark the long-term outcomes of survivors.

**Conclusions**

Web-based screening software has major benefits compared to paper-based screening however the implementation has shown to be difficult and there are important barriers to consider. In order to successfully implement a new web-based triage-tool, health professionals need time and support to use it. E-mail addresses should be queried at hospital admission so that it won't be necessary to collect the e-mail address after hospital discharge. In both web-based and paper-based population there was a large prevalence of survivors with possible mental, physical and nutritional problems and we suggest ICU follow-up care in order to address these problems. We think that our software is a starting point of making ICU follow-up care feasible and effective.

## References

1. Angus DC, Carlet J. Surviving intensive care: a report from the 2002 Brussels Roundtable. Intensive Care Med. 2003;29:3.
2. Oeyen SG, Vandijck DM, Benoit DD, Annemans L, Decruyenaere JM. Quality of life after intensive care: a systematic review of the literature. Crit Care Med. 2010;38:12.
3. Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. Crit Care Med. 2012;40:2.
4. van der Schaaf M, Beelen A, Dongelmans DA, Vroom MB, Nollet F. Functional status after intensive care: a challenge for rehabilitation professionals to improve outcome. J Rehabil Med. 2009;41:5.
5. Tan T, Brett SJ, Stokes T, Guideline Development G. Rehabilitation after critical illness: summary of NICE guidance. BMJ. 2009;338.
6. Korkeila K, Suominen S, Ahvenainen J, Ojanlatva A, Rautava P, Helenius H et al. Non-response and related factors in a nation-wide health survey. Eur J Epidemiol. 2001;17:11.
7. van der Schaaf M, Beelen A, Dongelmans DA, Vroom MB, Nollet F. Poor functional recovery after a critical illness: a longitudinal study. J Rehabil Med. 2009;41:13.
8. van Gelder MM, Bretveld RW, Roeleveld N. Web-based questionnaires: the future in epidemiology? Am J Epidemiol. 2010;172:11.
9. Coons SJ, Eremenco S, Lundy JJ, O'Donohoe P, O'Gorman H, Malizia W. Capturing Patient-Reported Outcome (PRO) Data Electronically: The Past, Present, and Promise of ePRO Measurement in Clinical Trials. Patient. 2015;8:4.
10. Cox CE, Wysham NG, Kamal AH, Jones DM, Cass B, Tobin M et al. Usability Testing of an Electronic Patient-Reported Outcome System for Survivors of Critical Illness. Am J Crit Care. 2016;25:4.
11. van der Schaaf M, Bakhshi-Raiez F, Van der Steen M, Dongelmans DA, De Keizer NF. Recommendations for the organization of intensive care follow-up clinics; report from a survey and conference of Dutch intensive cares. Minerva Anestesiol. 2015;81:2.
12. van de Klundert N, Holman R, Dongelmans DA, de Keizer NF. Data Resource Profile: the Dutch National Intensive Care Evaluation (NICE) Registry of Admissions to Adult Intensive Care Units. Int J Epidemiol. 2015;44:6.
13. Dutch National Intensive Care Evaluation (NICE) registry http://www.stichting-nice.nl Accessed 08.11.2016.
14. Mahieu GR. Follow-up system for intensive care patients: Preliminary evaluation of workflow and usability. Amsterdam: University of Amsterdam; 2014.
15. Boren MT, Ramey J. Thinking aloud: Reconciling theory and practice. Ieee Transactions on Professional Communication. 2000;43:3.
16. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67:6.
17. Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992;30:6.
18. Aaronson NK, Muller M, Cohen PD, Essink-Bot ML, Fekkes M, Sanderman R et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. J Clin Epidemiol. 1998;51:11.
19. Brewin CR, Rose S, Andrews B, Green J, Tata P, McEvedy C et al. Brief screening instrument for post-traumatic stress disorder. Br J Psychiatry. 2002;181.
20. Elia M. Screening for malnutrition: A multidisciplinary responsibility. Development and Use of the Malnutrition Universal Screening Tool ('MUST') for Adults. Redditch: BAPEN; 2003.

21. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nurs Health Sci. 2013;15:3.
22. Brooke J. SUS: A Quick and Dirty Usability Scale. In: Usability Evaluation in Industry. London: Taylor & Francis; 1996. p. 189–94.
23. IBM Corp. IBM SPSS Statistics for Windows. Version 24.0. Armonk, NY. IBM Corp.
24. Centraal Bureau voor de Statistiek (CBS). In: Statline. . http://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=71102ned&D1=0-3,30-34&D2=0-10&D3=0,l&HDR=G2,T&STB=G1&VW=T. Accessed 01.02.2017.
25. Cuthbertson BH, Rattray J, Campbell MK, Gager M, Roughton S, Smith A et al. The PRaCTICaL study of nurse led, intensive care follow-up programmes for improving long term outcomes from critical illness: a pragmatic randomised controlled trial. BMJ. 2009;339.
26. Jones C, Skirrow P, Griffiths RD, Humphris GH, Ingleby S, Eddleston J et al. Rehabilitation after critical illness: a randomized, controlled trial. Crit Care Med. 2003;31:10.
27. Elliott D, McKinley S, Alison J, Aitken LM, King M, Leslie GD et al. Health-related quality of life and physical recovery after a critical illness: a multi-centre randomised controlled trial of a home-based physical rehabilitation program. Crit Care. 2011;15:3.
28. Zuidgeest M, Hendriks M, Koopman L, Spreeuwenberg P, Rademakers J. A comparison of a postal survey and mixed-mode survey using a questionnaire on patients' experiences with breast care. J Med Internet Res. 2011;13:3.
29. Brewin CR, Andrews B, Valentine JD. Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. J Consult Clin Psychol. 2000;68:5.
30. Baldwin FJ, Hinge D, Dorsett J, Boyd OF. Quality of life and persisting symptoms in intensive care unit survivors: implications for care after discharge. BMC Res Notes. 2009;2.
31. Unroe M, Kahn JM, Carson SS, Govert JA, Martinu T, Sathy SJ et al. One-year trajectories of care and resource utilization for recipients of prolonged mechanical ventilation: a cohort study. Ann Intern Med. 2010;153:3.

## Data sharing statement

We obtained permission from the research board of the NICE registry and the participants to use data at the time of the study. The NICE board assesses each application to use the data on the feasibility of the analysis and whether or not the confidentiality of patients and ICUs will be protected. To protect confidentiality, raw data from ICUs is never provided to third parties. For the analyses described in this paper, we used an anonymized dataset. The use of anonymized data does not require informed consent in the Netherlands.

## Ethics

The NICE registry is registered according to the Dutch Personal Data Protection Act. The need for ethical approval for this study was waived by the Medical Ethics Committee of the Academic Medical Center and stored under number W17-354.

## Acknowledgements

We would like to thank all ICU survivors and health professionals of the participating hospitals who were willing to participate in this study. We would like to thank ItéMedical for all services provided with respect to the development of the web-based triage-tool and the technical support during the pilot- study.

## Author's contribution

IvB gave the training to use the triage-tool, conducted all semi-structured interviews with the health professionals, transcribed the interviews verbatim, coded the interviews and drafted the manuscript.

FBR gave the training to use the triage-tool, coded the interviews and helped to draft the manuscript.

NdK participated in the design and coordination of this study.

DAD helped in analysing and interpreting the results.

MvdS participated in the design and coordination of this study.

All authors discussed the themes and statements of the coding, read and approved the final manuscript.

## TITLES OF TABLES

Table 1. Recommendations for eligibility of ICU survivors for ICU follow-up clinics [11]

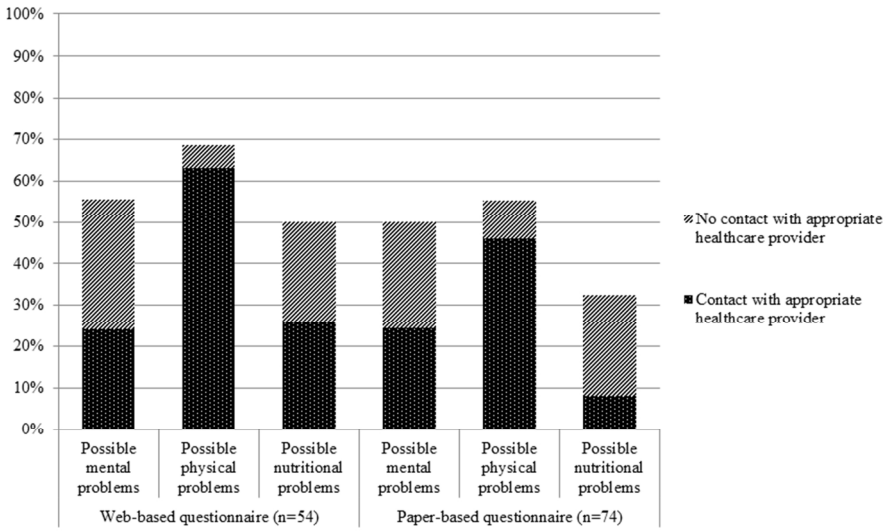
Table 2. Validated questionnaires used during this study

Table 3. Themes exemplifying the statements of the 14 health professionals interviewed

Table 4. Characteristics of ICU survivors who returned the questionnaires

## TITLES OF FIGURES

Figure 1. Prevalence of mental problems, physical problems and nutritional problems




190x142mm (300 x 300 DPI)

**Work-related questions**

1. Describe the job you had before your ICU admission
2. Which situation reflects your situation best: before my ICU admission I was/I had:
    a. employed
    b. self-employed
    c. partially incapacitated
    d. (early) retired
    e. unemployed / looking for employment
    f. fully incapacitated
    g. social assistance
    h. fulltime ‘man around the house'/’woman around the house’
    i. student
3. What were your main tasks in the job you had before your ICU admission?
    a. mostly physically demanding tasks
    b. mostly mentally demanding tasks
    c. a mixture of physically and mentally demanding tasks
    d. no physically or mentally demanding tasks
4. According to you contract, how many hours did you work before your ICU admission?
5. How many hours did you work before your ICU admission?
6. Describe your current job
7. Which situation reflects your current situation best: after my ICU admission I was/I had:
    a. employed
    b. self-employed

c. partially incapacitated

d. (early) retired

e. unemployed / looking for employment

f. fully incapacitated

g. social assistance

h. fulltime ‘man around the house'/’woman around the house’

i. student

8. What are your main tasks in your current job?

a. mostly physically demanding tasks

b. mostly mentally demanding tasks

c. a mixture of physically and mentally demanding tasks

d. no physically or mentally demanding tasks

9. According to your current contract, how many hours do you work?

10. How many hours do you work after your ICU admission?

11. Are you disturbed by your health status within your current job?

a. no

b. a bit

c. strongly

12. Did your financial situation decline compared to the situation before your ICU admission?

**Common problems after an ICU admission**

| | | |
|---|---|---|
| Do you experience decreased vision compared to the situation before ICU admission? | Yes | No |
| Do you experience decreased hearing compared to the situation before ICU admission? | Yes | No |
| Do you experience decreased taste compared to the situation before ICU admission? | Yes | No |
| Do you experience decreased voice compared to the situation before ICU admission? | Yes | No |
| Do you have more problems with your balance compared to your situation before ICU admission | Yes | No |
| Do you experience a change in defecation (consistency, frequency) compared to your situation before ICU admission? | Yes | No |
| Do you experience more problems urinating compared to the situation before ICU admission? | Yes | No |

| | | |
|---|---|---|
| Do you experience decreased sexual functions compared to the situation before ICU admission? | Yes | No |
| Do you experience a change menstruation compared to the situation before ICU admission? | Yes | No |
| Do you experience more stiffness of your joints compared to the situation before ICU admission? | Yes | No |
| Do you experience more muscle weakness compared to the situation before ICU admission? | Yes | No |
| Do you experience more hair loss compared to the situation before ICU admission? | Yes | No |
| Do you experience more itching or exfoliation of your skin compared to the situation before ICU admission? | Yes | No |

**Visits to healthcare professionals after ICU admission**

| | | |
|---|---|---|
| Did you visit a general practitioner within the last 3 months? | Yes | No |
| Did you visit a district nurse or did you receive professional home care within the last 3 months? | Yes | No |
| Did you visit a physical therapist within the last 3 months? | Yes | No |
| Did you visit an occupational therapist within the last 3 months? | Yes | No |
| Did you visit a speech therapist within the last 3 months? | Yes | No |
| Did you visit a dietician within the last 3 months? | Yes | No |
| Did you visit a social worker within the last 3 months? | Yes | No |
| Did you visit a psychologist within the last 3 months? | Yes | No |
| Did you visit a psychiatrist within the last 3 months? | Yes | No |
| Did you visit a rehabilitation specialist within the last 3 months? | Yes | No |
| Did you visit a pulmonologist within the last 3 months? | Yes | No |

| | | |
|---|---|---|
| Did you visit a dermatologist within the last 3 months? | Yes | No |
| Did you visit a neurologist within the last 3 months? | Yes | No |
| Did you visit an orthopaedist within the last 3 months? | Yes | No |

Did you visit another healthcare professional within the last 3 months? If yes, which healthcare professional?

# Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No. Item | Guide questions/description | Reported on Page # |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| 1. Inter viewer/facilitator | Which author/s conducted the inter view or focus group? | 8 |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | 1 |
| 3. Occupation | What was their occupation at the time of the study? | 8 |
| 4. Gender | Was the researcher male or female? | - |
| 5. Experience and training | What experience or training did the researcher have? | - |
| *Relationship with participants* | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | 5 |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 5-8 |
| 8. Interviewer characteristics | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | - |
| **Domain 2: study design** | | |
| *Theoretical framework* | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 8 |
| *Participant selection* | | |
| 10. Sampling | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 5-8 |
| 11. Method of approach | How were participants approached? e.g. face-to-face, telephone, mail, email | 5-8 |
| 12. Sample size | How many participants were in the study? | 9 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | - |
| *Setting* | | |
| 14. Setting of data collection | Where was the data collected? e.g. home, clinic, workplace | 8 |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | - |
| 16. Description of sample | What are the important characteristics of the | 9 |

| | | |
|---|---|---|
| | sample? e.g. demographic data, date | |
| *Data collection* | | |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | N/A |
| 18. Repeat interviews | Were repeat inter views carried out? If yes, how many? | N/A |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | 8 |
| 20. Field notes | Were field notes made during and/or after the inter view or focus group? | - |
| 21. Duration | What was the duration of the inter views or focus group? | 9 |
| 22. Data saturation | Was data saturation discussed? | - |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | N/A |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| 24. Number of data coders | How many data coders coded the data? | 8 |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | N/A |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | 8 |
| 27. Software | What software, if applicable, was used to manage the data? | Word |
| 28. Participant checking | Did participants provide feedback on the findings? | 9-11 |
| *Reporting* | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | Table 3 |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | 12-14 |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | 9-11 |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | 12-14 |

# STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
# Checklist for cohort, case-control, and cross-sectional studies (combined)

| Section/Topic | Item # | Recommendation | Reported on page # |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | 1 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | 2 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 4 |
| Objectives | 3 | State specific objectives, including any pre-specified hypotheses | 4 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | 5-8 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 5-8 |
| Participants | 6 | (*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up<br>*Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls<br>*Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants | 5<br>Table 1 |
| | | (*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed<br>*Case-control study*—For matched studies, give matching criteria and the number of controls per case | |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 6-8<br>Table 2 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | 6-8 |
| Bias | 9 | Describe any efforts to address potential sources of bias | |
| Study size | 10 | Explain how the study size was arrived at | 5-8 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | 6-7<br>Table 2 |

| | | | |
|---|---|---|---|
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | 8 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | - |
| | | (*c*) Explain how missing data were addressed | - |
| | | (*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed<br>*Case-control study*—If applicable, explain how matching of cases and controls was addressed<br>*Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy | - |
| | | (*e*) Describe any sensitivity analyses | - |
| **Results** | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 9-12 |
| | | (b) Give reasons for non-participation at each stage | 9-12 |
| | | (c) Consider use of a flow diagram | - |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | Table 4 |
| | | (b) Indicate number of participants with missing data for each variable of interest | Table 4 |
| | | (c) *Cohort study*—Summarise follow-up time (eg, average and total amount) | |
| Outcome data | 15* | *Cohort study*—Report numbers of outcome events or summary measures over time | |
| | | *Case-control study*—Report numbers in each exposure category, or summary measures of exposure | |
| | | *Cross-sectional study*—Report numbers of outcome events or summary measures | 9-12<br>Table 4 |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 9-12 |
| | | (*b*) Report category boundaries when continuous variables were categorized | Table 2 |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | - |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | - |

| | | | |
|---|---|---|---|
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | 12-13 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 14 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 12-14 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 12-14 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 3 |

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.