PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	Lessons learned during the implementation of a web-based triage-tool for Dutch intensive care follow-up clinics
AUTHORS	van Beusekom, Ilse; Bakhshi-Raiez, Ferishta; de Keizer, Nicolette; Dongelmans, Dave; van der Schaaf, Marike

VERSION 1 – REVIEW

REVIEWER	Shoshana Landow Brown Univeristy, USA
REVIEW RETURNED	20-Feb-2018

GENERAL COMMENTS	I question why there is such a long interval for follow up - 3 months is a long time. I wish there had been a wing of the study in which the questionnaire went out at 1 month, and I think the response rate would be better if it were sent out sooner, and the support to patients and caregivers more effective. Is there data supporting why the interval is so long after discharge. I would also like to know if there is any data that could be collected on the nonresponders; for example, is it possible that some of them died in the interval, or went to long-term care facilities? Overall, however, a nice little comparison of methods of followup that seems to support using both options, electronic and paper, to capture as many patients as possible.

REVIEWER	Dr Fiona Baldwin Royal Sussex County Hospital, UK
REVIEW RETURNED	19-Mar-2018

GENERAL COMMENTS	Seemed very promising. No mention of ethics. High proportion of patients not enrolled and disappointing response to those enrolled which is major limitation. Why was software so difficult? Interesting discussion there.

REVIEWER	Gillian Colville St George's Hospital, London UK
REVIEW RETURNED	15-Apr-2018

GENERAL COMMENTS	Bmj open review In this study the authors examine whether the mode of provision of a series of questionnaires used to collect information on ICU patients followed up 3 months after discharge is associated with differences in response rate, rate of missing data, severity of symptoms or sociodemographic factors. They compare administration of the questionnaire on paper via the post with administration online in a

	group of 128 patients treated on 8 different units. They hypothesise that response rate and completeness of data will be better with the online version, but find, in this real world study, that a number of patients, particularly those who are older, prefer to fill the questionnaires on paper. The hypothesis that data will be more complete in the online version is upheld, however. Figure 1 is a useful reminder of the need for follow up for this group of patients as it shows that around half of the patients who responded to the survey, irrespective of mode of administration, report significant problems with physical and/or mental health and/or nutrition and that , in the case of those with mental health and nutrition related problems they less likely to be in contact with relevant services at the time of follow up. The authors do not present statistics on this but this is how it appears from the FIgure. The fact that the take up of the online version of the questionnaire was not as good as hoped, is disappointing but highlights the importance of testing ideas out in the real world. As the authors observe it may be that this population is not fully ready yet for communication via the internet, given that by definition it is predominantly made up of older people, but in the future when internet use/email is ubiquitous it seems likely that questionnaires such as this will be mainly administered electronically. It is important also to note that nursing staff found the software difficult to master. Is this why the number of eligible patients was relatively low? Or was this mainly because nurses could not find email details and had to phone patients to get them? If nurses ended up phoning patients quite often because they did not get a response or because they did not have an email address, would it not have made sense to ask the questions on the phone? The fact that over 40% did not respond to either mode of delivery of the questionnaire limits the generalisability of the questionnaire findings and suggests that alternative methods of contacting patients, such as phoning, might be worth trying , in order to reach as many people as possible. DId the authors consider administration via phone text with hyperlink as opposed to email? Or do they think the same problem would have applied? The fact that ptsd scores were higher in the web based group may be an artefact as the online group were found to be younger and younger age has been found to be a risk factor for ptsd in meta analyses (eg Ozer et al, Brewin et al). Is there any more information on why only 45% approached to fill in the questionnaires? Was this partly to do with the difficulty the caregivers had with the software or is there a possibility that some sub groups of patients were more likely to be contacted than others? - this has implications for the generalisability of findings. P7 The authors give 10% as the number that will refuse follow up. How does this figure fit with the fact that only 60% were prepared to fill in the survey/attend the clinic? Top p14 The authors state that the difference relating to

	psychological health was not significant - it should not be reported as different in that case. The term 'caregivers' may be confusing to readers, who may assume the authors are referring to relatives when they use this. Personally I would prefer a less ambiguous phrase such as 'health professionals'.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Shoshana Landow
Institution and Country: Brown University, USA
Please state any competing interests or state 'None declared': None declared

1. I question why there is such a long interval for follow-up - 3 months is a long time. I wish there had been a wing of the study in which the questionnaire went out at 1 month, and I think the response rate would be better if it were sent out sooner, and the support to patients and caregivers more effective. Is there data supporting why the interval is so long after discharge.

   Thank you for raising this question. We used the recommendations by Van der Schaaf et al. for our study. These recommendations were formulated based on a national survey among Dutch ICUs and the available literature. Subsequently, in a round table conference stakeholders discussed and voted on a final approval of the recommendations [1]. This resulted in, among others, a three-months interval for follow-up after hospital discharge. Also in the United Kingdom, a majority of ICU follow-up clinics invite the patients for their 1st clinic appointment 3 months after ICU or hospital discharge [2].

   For this pilot study we created a new tool which we wanted to test in the 'real world' and therefor the interval for follow-up was similar to current practice, i.e. nine weeks after hospital discharge the ICU survivor received an invitation to fill out the questionnaires and the first visits to the post-ICU clinic was scheduled 12 weeks after hospital discharge.

2. I would also like to know if there is any data that could be collected on the non-responders; for example, is it possible that some of them died in the interval, or went to long-term care facilities?

   Thank you for this comment. We tried to clarify this in the manuscript:
   1) Before sending the questionnaires, the healthcare professionals checked if the ICU survivor was alive. We described it in the manuscript as followed: *'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.'*

   2) Non-responders were phoned by the healthcare professionals to ask for the reason for non-response. In the manuscript this is clarified as follows: *'Ninety-three (42.1%) survivors did not respond to the invitation. Twenty-eight (12.7%) non-responders 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'.

3) It is possible that ICU survivors died after sending the questionnaire or that ICU survivors went to long-term care facilities. However, we have no additional information on that. We conducted additional analyses on the differences *between non-responders and responders* and have added the following text: '*There were no significant differences in characteristics between non-responders and responders.*'

3. Overall, however, a nice little comparison of methods of follow-up that seems to support using both options, electronic and paper, to capture as many patients as possible.

Thank you.

Reviewer: 2

Reviewer Name: Dr. Fiona Baldwin
Institution and Country: Royal Sussex County Hospital, UK
Please state any competing interests or state 'None declared': None declared

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1. Seemed very promising. No mention of ethics.

Thank you for your comment, this is indeed a very important subject. At the end of the manuscript we had included a paragraph about the 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.'*

Moreover, we now added a data sharing statement which contains more information about the use of the data and the use of inform consents in the Netherlands: '*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.'*

VERSION 2 – REVIEW

REVIEWER	Gillian Colville St George's Hospital, London UK
REVIEW RETURNED	12-Jul-2018

GENERAL COMMENTS	Happy with the changes. Authors have addressed reviewer's comments comprehensively.