Dear Dr. Saltman,

Please find enclosed a revised version of the manuscript "Young patients’, parents’, and survivors’ communication preferences in paediatric oncology: Results of online focus groups" (Manuscript ID 1553132051146415). Thank you for the constructive comments of the reviewers and for giving us the opportunity to revise the manuscript. In this letter, I will outline how we have changed the paper in response to the issues raised by the three reviewers.

Reviewer 1

As suggested by the reviewer, we have added some details concerning the reactions in the different focus groups, such as the number of postings and the number of topics covered (Table 4).

Reviewer 2

1. The reviewer refers to the large differences between the numbers of respondents who were approached for the study and the numbers of respondents who actually participated. The reviewer requests our suggestions on how to improve response rates in future studies.

First, we would like to stress that the response rates in our study are not uncommon for studies in which online focus groups are used. As we described in the discussion, the majority of these studies use self-selection through the Internet as a method to include respondents, which incorporates the risk of selection bias (p. 19). However, direct comparison of response rates is difficult, considering the fact that online focus groups have not been used before within groups of paediatric cancer patients and their parents.

Focus groups are typically meant to elicit data on the views and opinions of small
groups of people. With this qualitative study, we did not aim to provide an overall picture of the needs and preferences of the various groups of participants. The study was aimed at increasing our understanding of processes which were hardly studied before. As is written in the discussion, emphasis is placed upon achieving a depth of understanding instead of upon generalization of the findings (p. 20). Therefore, the findings of this study are regarded as exploratory and will be studied in more detail and in larger groups in a study currently being conducted (p. 20).

The gap between the number of eligible participants who were approached for the study and the actual number of participants can partly be explained by the nature of the sample. As is described on page 7, in two of the families that did not participate despite their initial consent, the child was severely ill at the start of the online focus group. This problem is inherent to the sample under investigation and cannot easily be overcome. In fact, the use of online focus groups, which allowed participants to respond from their home and at any time convenient to them, will probably have facilitated participation for patients and parents currently involved in active treatment and is therefore recommended for future research (p. 19). Based on the differences in participation rates between the two ways of recruitment, we have also added a recommendation to further investigate this issue (p. 19). We will describe the advantages and disadvantages of the online focus group methodology in more detail in a manuscript currently in preparation.

2. In line with the suggestion of the reviewer, a sentence has been added to the conclusions (p. 21), in which we advocate the use of a screening tool for evaluating patients’ and parents’ communication needs and preferences. Based on the focus group results, we have developed a questionnaire and vignettes for measuring patients’ and parents’ communication preferences in paediatric oncology. The questionnaire combines information about aspects considered as important in communication with information about actual experiences with these aspects. In that way, it can reveal aspects of communication that need improvement and may therefore be used as a screening tool in the future. The questionnaire and the vignettes are currently being used in a larger sample of childhood cancer patients and their parents, which will provide more insight into the needs and preferences of these groups and thereby also into the generalizability of the findings of this qualitative study. Reference to this study currently being conducted is now made on page 21.

Reviewer 3

1. Questions which were used in the young patients’ focus group were added to give an impression of the kind of questions used in the focus groups (Table 3). Questions for the other groups of participants were comparable in content, but the wording was adapted to the age range of the participants (p. 8).

As is described on page 9, topics for the focus groups were derived from literature. The discussion between participants was not led in any specific direction; participants were free to emphasize any topics they thought to be of importance. Participants were invited to introduce new issues they considered
relevant in communication in paediatric oncology on the last two days of the focus groups (p. 8). In this way, we think to have ensured an adequate coverage of issues that are relevant for patients, parents and survivors. Since children in active treatment, parents, as well as survivors could be actively engaged in the focus groups over a one-week period (see p. 19 and Table 4), we believe that the questions were appropriate even for young children. However, there appeared to be a difference in focus group dynamics between the age groups. Young patients tended to direct their comments to the moderators rather than to each other, whereas adolescent patients and survivors developed a more interactive way of responding by reacting actively to the contributions of other participants. This has been added to page 8.

2. Table 5 (which was originally Table 3) has been expanded. It now presents an overview of the needs and preferences expressed in the three different groups of participants.

3. Percentages were added to Table 1.
The reviewer suggests that children and parents with stronger preferences for participation in communication and decision making may have been more likely to participate in the study, leading to a selection bias which could overestimate the preference for participation in communication and decision making. This possibility has been added to the discussion (p. 20). Focus groups are, however, typically meant to elicit data on the views of small groups of people instead of being focused on generalization of the findings (this issue is discussed in more detail in our response to the first comment of reviewer 2).

4. To our knowledge, online focus groups have not previously been used for children in paediatric settings. A sentence describing this has been added to the discussion (p. 19). Young patients, parents, and survivors could be actively involved in the online focus groups and provided elaborate responses. This new methodology can therefore be regarded as a feasible tool to investigate the perspectives of hard-to-include groups of respondents, such as children in active treatment for cancer and their parents (p. 19). Moreover, the online focus group methodology does not only provide the opportunity to consider the often neglected opinions of children (see p. 4), but also allows the comparison of the perspectives of differing populations, which the reviewer points out as a major asset of this study.

5. We have changed the standard deviations in Table 2 into ranges.

We hope these changes will adequately meet the comments. We look forward to hearing from you after you have had a chance to examine this version of the paper.

Sincerely,

Marieke Zwaanswijk, PhD