

Experiences of hospitalized adult patients and their relatives concerning rooming-in

Development and content validity of a patient-survey and relative-survey

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ABSTRACT

Background: Rooming-in of relatives with hospitalized adult patients offers relatives to stay for 24 hours a day in the hospital. Little is known about rooming-in experiences of adult patients and relatives.

Aim: To (1) develop two surveys to assess rooming-in experiences of hospitalized adult patients and their relatives during hospital admission, and establish content validity; (2) use these surveys to describe their rooming-in experiences targeted at developing procedures.

Method: This two-part study was conducted at a university hospital in the Netherlands. In the first part a patient- and relative-survey were developed and validated following three stages: item generation, item review and a cross-sectional pilot. In the second part these surveys were cross-sectionally administered to patients and relatives. An item pool was scored by an expert panel using the content validity index, and descriptive statistics were performed to describe rooming-in experiences.

Results: A 22-item patient-survey and 37-item relative survey were developed, and were both considered content valid (S-CVI/Ave = 0.90). Fifty-one patients and 60 relatives were included in the second part of the study. Rooming-in experiences were very good according to patients (80% ≥ 8) and relatives (73% ≥ 8). Relatives (90%) were involved in care, reported higher levels of emotional burden (55%), almost two-third (63%) did not experienced physical burden, and 28% perceived worse sleep quality. Patients felt more comfortable (84%) and calmer (70%) due to a relative's presence.

Conclusion and implications: Two content valid surveys were developed that assess rooming-in experiences of hospitalized adult patients and their relatives during hospital admission. Results of this study may help to develop procedures regarding rooming-in. Clear information about healthcare policies is essential to improve patient- and relative satisfaction, guarantee continuity of care, and increase quality of care.

Keywords: instrument development, content validity, rooming-in, adult inpatients, relatives

NEDERLANDSE SAMENVATTING

Achtergrond: Rooming-in als onderdeel van familieparticipatie richt zich op het 24 uur mogen verblijven van een naaste bij de patiënt op de kamer. Wegens beperkte literatuur blijft richtlijnontwikkeling achter.

Doel: Het (1) ontwikkelen van twee rooming-in vragenlijsten voor volwassen patiënten en naasten die opgenomen zijn op verpleegafdelingen, en bepalen van content validiteit; (2) deze vragenlijsten gebruiken om hun ervaringen met rooming-in te beschrijven die gericht zijn op het ontwikkelen van procedures.

Methode: Deze tweedelige studie richtte zich eerst op ontwikkeling en validatie bestaande uit item generatie, item review en een cross-sectionele pilot. In het tweede deel werden deze vragenlijsten cross-sectioneel uitgezet bij patiënten en naasten in een universitair ziekenhuis in Nederland. Een itempool werd ontwikkeld en door experts beoordeeld op basis van de content validiteit index, en beschrijvende statistiek werd toegepast om resultaten te beschrijven.

Resultaten: Een 22-item patiënten-vragenlijst en 37-item naaste-vragenlijst is ontwikkeld en zijn beiden content valide ($S-CVI/Ave = 0.90$). In het tweede deel hebben 51 patiënten en 60 naasten geparticipeerd. De ervaring met rooming-in was erg goed volgens patiënten (80% ≥ 8) en naasten (73% ≥ 8). Naasten vonden het prettig betrokken te worden in de zorg (90%), hadden het in hogere mate emotioneel zwaar (55%), bijna twee derde (63%) ondervond geen lichamelijke last, en 28% ervaarden slechte slaap. Patiënten voelden zich comfortabeler (84%) en rustiger (70%) door de aanwezigheid van een naaste.

Conclusie: Twee content valide vragenlijsten zijn ontwikkeld en meten de ervaringen met rooming-in bij volwassen patiënten en hun naasten tijdens een ziekenhuisopname. Resultaten van deze studie kunnen bijdragen aan de ontwikkeling van richtlijnen omtrent rooming-in. Het verstrekken van duidelijke informatie over ziekenhuisbeleid is essentieel om de tevredenheid van patiënten en hun naasten te verbeteren, continuïteit van zorg te waarborgen, en kwaliteit van zorg te verhogen.

Trefwoorden: vragenlijstontwikkeling, content validiteit, rooming-in, volwassen patiënten, naasten

INTRODUCTION

Over the last decade, concepts of patient- and family-centered care (PFCC) have emerged, including the influence of the hospital environment on patient outcomes¹⁻⁴. The patient's hospital experience is increasingly important as hospitals aim to satisfy patients with respect to care and health-related quality of life⁵. Numerous hospitals hold the view that excellent care involves family presence, support, and involvement in patient care^{1,3,4,6,7}. As a result, more and more hospitals are transitioning from multi-bedded to single-bedded patient rooms⁸⁻¹¹. Single rooms enhance privacy and make it easier to involve relatives in patient care without disturbing other patients⁸.

Family participation can be described as the involvement of relatives in caring for the patient^{12,13}, and it consists of being present, receiving care, having needs met, communication, decision making, and contributing to care¹⁴. Increased family participation improves patient and family satisfaction, enhances continuity of care, prevents hospital readmissions, and provides opportunities for cost savings^{1,3,6,15}.

Family participation also includes rooming-in, which is described as the presence of a family member, close friend, or acquaintance of the patient during hospitalization, including overnight stays in the room^{16,17}. Rooming-in was first introduced when mothers were allowed to stay with their newborns¹⁸. Today, rooming-in is also available for hospitalized adult patients who suffer from acute confusion, memory lapses, and language and behavioral difficulties, along with patients who are terminally ill^{13,19,20}.

Although hospitals in the Netherlands increasingly provide rooming-in opportunities and encourage relatives to participate in care, research about the effects of rooming-in is limited^{13,16,17,19-21}. Only one randomized controlled trial in 24 elderly surgical patients was performed, using non-specific rooming-in questionnaires to evaluate the effects of rooming-in on patient outcomes¹⁹. Rooming-in was considered feasible and highly satisfactory by relatives, on the condition that the expectations of staff and relatives are set in advance¹⁹. Other studies describe rooming-in as valuable^{13,17,21} and provide a sense of comfort to relatives¹⁶, although rooming-in can also be burdensome to relatives in terms of emotional, physical, social, and financial aspects¹³. However, evidence about the effects of rooming-in is lacking because these observational studies did not have robust designs exploring rooming-in.

As evidence-based practice is the standard for care, collecting reliable and valid outcome data is essential. Patient-reported outcome measures (PROMs) are defined as standardized and validated questionnaires to measure the perception of patients regarding their functional well-being and health status²². As more hospitals worldwide adopt a PFCC approach, the number of single-bedded hospitals will increase, and rooming-in will become

more available. Therefore, there is a need for an instrument that assesses rooming-in experiences of patients and relatives. Such a measure can provide information to develop procedures regarding rooming-in.

Therefore, a study with a two-part objective was set up. The first objective was to develop two questionnaires to assess rooming-in experiences of hospitalized adult patients who were admitted to general nursing departments and their relatives, and to establish content validity. The second objective was to describe rooming-in experiences of hospitalized adult patients and their relatives, targeted at developing procedures regarding rooming-in.

METHODS

Design

This two-part study was conducted at a university hospital in the Netherlands. The first part included the development and content validity of two questionnaires. Item generation, item review and a cross-sectional pilot resulted in two surveys: a patient-survey and relative-survey. In the second part, these surveys were administered in general departments using a cross-sectional observational design to gain knowledge about rooming-in experiences of adult patients and relatives. Figure 1 represents the study.

[Figure 1]

Setting and participants

Part 1

An expert panel (junior and senior researchers, a nursing science student, an oncology nurse and team managers) with expertise in methodology, outcome measurement, and rooming-in were approached to review draft versions. The number of required experts is at least 5 and at most 10²³. Eleven experts were approached through purposive sampling to maximize information, and take into account non-response^{22,24}.

For the pilot a convenience sampling method was used for patient and relative recruitment²⁵. A total of 13 patients and their relatives were asked to participate. Participants were eligible by meeting the following inclusion criteria: 1) stayed at least two nights in general nursing departments, 2) had sufficient comprehension of Dutch or English language, and 3) were cognitively able to respond to questions. Patients were excluded if they were nursed in barrier or isolation, delirious or terminally ill patients, and those in intensive care departments.

Part 2

Convenience sampling was used to recruit patients and relatives²⁵. A sample size of at least 50 patients and their relatives was considered to be sufficient to achieve good methodological quality²². An inclusion of 60 participants was intended²⁶. The inclusion- and exclusion criteria were defined in the same way as in the pilot.

Data collection and procedures

Data collection for the first part of the study took place between February 2019 and March 2019, and for the second part between March 2019 and May 2019.

Part 1

To generate a pool of items for the patient-survey and the relative-survey, a review of the literature and transcripts of previously conducted interviews with relatives were performed by a student nurse (B.S.). The guidelines of the COConsensus based Standards for the selection of health Measurement Instruments (COSMIN)²² and Polit and Beck²⁴ were followed.

The two draft surveys derived from the item pool included varied response options across items: yes/no responses, four or five-point Likert scales (never–always; totally disagree–totally agree), and open-ended questions²⁴. Clear and unambiguous items were aimed, and words were carefully chosen to adhere to a 6th – 7th grade reading level²⁴. Readability was reviewed by a linguist affiliated with a university hospital.

The two draft surveys were distributed to the panel of experts to test content validity. Content validity is defined as “the degree to which the content of an instrument is an adequate reflection of the construct to be measured”²², and consist of three aspects: relevance, comprehensibility and comprehensiveness. The expert panel received an invitation to participate via email with information about the purpose of the study, instructions, and the two draft surveys. Experts were asked to provide feedback by email within two weeks about the following characteristics: relevance, comprehensibility, comprehensiveness, length of the survey, and its appropriateness for the target population^{24,27}. Also recommendations for improvement were requested. Relevance was scored on a 4-point Likert scale (1= not relevant, 2 = somewhat relevant, 3 = relevant and 4 = very relevant)²³. The other characteristics were collected using comments of the experts. After feedback was received and used to revise items, a second email was sent to the same experts, requesting a global review and to provide feedback within one week.

Subsequently the initial surveys were pilot tested in patients and relatives during their hospital stays. The researcher called departments twice a week and regularly visited for recruitment. Approval was obtained from bedside nurses prior to approaching patients and

relatives. The pilot included the following characteristics: (a) face validity, which refers to whether the instrument at first impression seemed to measure perspectives on rooming-in²⁷, (b) feasibility, (c) problems with data collection methods and (d) adequacy of instrumentation^{24,27}. Additional questions were added to the initial surveys about relevance, comprehensiveness, and comprehensibility of items²².

After face validity was established, patients and relatives were invited to complete the surveys and results were discussed with participants. Amended versions were reviewed by a linguistic expert before they were applied in the second part of the study.

Part 2

The researcher called departments twice a week and regularly visited for recruitment. Additionally, patient files were checked for rooming-in notes to maximize recruitment. Eligible participants received information about the study and after their verbal consent, the surveys were completed during hospital stay, and the researcher set up an appointment to collect the surveys.

Data analysis

Part 1

Thematic content analysis was applied to both the literature and transcripts to identify potential questionnaire items^{24,28}. Emerging themes were discussed among researchers, and the credibility of findings was established by seeking agreement with a coresearcher^{24,28}.

A content validity index was calculated for relevance at item level (I-CVI) and scale level (S-CVI)²³. I-CVI is the proportion of experts who rate its content as valid (3 or 4) and is divided by the total number of experts. When data was missing, the expert was emailed with the request to provide feedback on missing items. If items were still missing afterward, the I-CVI was calculated by dividing the number of experts who gave rating of 3 or 4 by total number of experts who rated these items. To calculate S-CVI, two different indices were calculated: 1) Universal Agreement (S-CVI/UA) as the proportion of items that experts scored as 3 or 4, and 2) Average (S-CVI/Ave) for all items combined represented the CVI of the scale²⁹. While S-CVI/UA decreases the likelihood of achieving total agreement when the number of experts increases, S-CVI/Ave may overestimate content validity but it is less constricted. S-CVI/Ave is preferred by Polit and Beck²⁹ although they recommend report both indices²⁹. Cut-off scores were at least 0.78 with ≥ 3 participants for I-CVI, ≥ 0.80 for S-CVI/UA, and ≥ 0.90 for S-CVI/AVE^{23,29}.

Other characteristics and suggestions for improvements were collected and discussed within the research team. Taking I-CVI into account and after consensus among researchers was reached, items were added, revised or removed.

Part 2

Statistical analyses was performed using IBM SPSS 24.0³⁰. Descriptive statistics were used to describe demographic, clinical, and social characteristics of participants. Nominal variables were coded as 1 (yes) and 2 (no), ordinal variables as either 1-4 or 1-5 for Likert scale options, and scale measures were used. Missing items were not imputed. Normally distributed data are presented as mean (standard deviation), and non-normally distributed data are presented as median (interquartile range).

Ethical considerations

This study was approved by the Medical Ethical Committee of Erasmus Medical Center (EMC 2017-2013). Because of the strictly observational and non-invasive nature of the study, the institutional review board waived the need for written informed consent. Potential participants were informed participation was voluntary, surveys were treated anonymously, and the decision to return a completed survey was their informed consent.

RESULTS

Part 1

Patient-survey

Content validity

The development process is presented in Appendix 1. The expert panel reviewed 38 items regarding practical aspects, psychosocial well-being, care delivery, sleep quality, and communication with nurses and physicians (Appendix 2). Thirty items (78.9%) were marked as relevant and I-CVI's ranged from 0.44-1.00 (Table 1). Eleven items had an I-CVI of 1.00, eleven had a score of 0.89 and eight had a score of 0.78. Eight items were considered irrelevant with a score of <0.78 and were related to background information (item 3), psychosocial well-being (item 13), sleep quality (items 22-26) and communication (item 33). S-CVI/Ave and S-CVI/UA were 0.85 and 0.29, respectively. Based on consensus among researchers, twenty-one items were removed due to their lack of relevance and/or their redundancy with other items. The recalculated S-CVI/Ave and S-CVI/UA were 0.90 and 0.38, respectively (Table 1). Four items related to practical aspects, psychosocial well-being, sleep quality, and care delivery were added.

After the second review, two items were added (practical aspects and sleep quality). Because some items were unclear to the experts, minor revisions were made in the response options, and an instruction was added resulting in a 22-item initial survey.

[Table 1]

Pilot

Eleven patients participated in the pilot. The survey was feasible, acceptable, and not too long. Minor revisions were made to make items more clear and unambiguous. As a result, a validated, 22-item survey was developed covering four domains: practical aspects, psychosocial well-being, sleep quality, and care delivery (Appendix 4). The survey also collected background characteristics (e.g. gender, age, relationship status, presence of relative, admission days, primary contact person, and EQ-5D to explore patients' state of health).

Relative-survey

Content validity

The development process is presented in Appendix 3. The expert panel reviewed 55 items regarding practical aspects, psychosocial well-being, physical well-being, financial aspects, leisure time, care delivery, sleep quality and communication with nurses and physicians (Appendix 2). Forty-seven items (85.5%) were marked as relevant, and I-CVI's ranged from 0.33-1.00 (Table 2). Twenty items had an I-CVI of 1.00, seventeen had a score of 0.89 and thirteen had a score of 0.78. Eight items were considered irrelevant with a score of <0.78; these were to background information (items 3, 4 and 11), practical aspects (items 16d and 17), psychosocial well-being (item 18) and sleep quality (items 39 and 40). S-CVI/Ave and S-CVI/UA were 0.85 and 0.35, respectively. Twenty items were removed due to their lack of relevance, their redundancy with other items and because the survey was considered to be too long. The recalculated S-CVI/Ave and S-CVI/UA were 0.90 and 0.37, respectively (Table 2). Six items on practical aspects (2 items), psychosocial well-being (1 item), care delivery (3 items) and background information (1 item) were added.

After the second review, minor revisions took place for clarity. One item (background information) was removed, and two items (practical aspects and sleep quality) were added. The result was a 36-item initial survey.

[Table 2]

Pilot

Twelve relatives participated in the pilot. The survey was considered feasible, acceptable, and not too long. Some questions were modified to make them easier to read, and response options and answers were reversed in order. One missing item (age) was identified and added during administration. As a result, a validated, 37-item survey was developed, covering eight domains: practical aspects, psychosocial well-being, physical well-being, financial, leisure time, sleep quality, care delivery, and communication with nurses and physicians (Appendix 2b). The survey also collected background characteristics (e.g. gender, age, relationship status, working status, presence, first time rooming-in, days of rooming-in and primary contact person).

Part 2

Sample characteristics of patients and relatives

A total of 51 patients and 60 relatives participated in the survey. Sample characteristics are presented in Table 3 and Table 4. The mean age of patients was 56 years ($SD = 18.4$), and the relatives varied in age between 41 and 55 years. Most relatives (72%) that roomed in were women, and 65% of the relatives were the spouse of the patient. The median number of rooming-in nights at the time of the survey was 3 for relatives and length of stay was 5 for patients, with both a minimum of 1 and maximum of 91 nights. Patients' mean self-perceived health score was 62 ($SD = 18.9$).

[Table 3]

[Table 4]

Background, practical and communication

Almost all relatives (90%) and patients (83%) appreciated the possibility of being together 24 hours a day. The main reasons for rooming-in given by patients and relatives, respectively, were restlessness (48%;52%), anxiety (47%;50%) and care delivery (42%;44%). Fifty-three percent of the relatives had an average workweek of 28 hours, and 70% of them had to arrange leave from work to make rooming-in possible. Also, almost two-third of the relatives (62%) incurred extra costs, especially parking (40%) and travel (37%) costs. In addition, 40% of the participants were offered rooming-in by nurses when admitted to a department. The other 60% had to request for rooming-in themselves or were informed by physicians. Furthermore, relatives (75%) and patients (80%) reported that hospital's department rules such as using facilities, attending consultations of physicians, allowing more visitors, and providing care were unclear.

Psychosocial and physical well-being

The following positive effects of rooming-in were frequently reported by relatives: being able to better support the patient (83%), patient feels safer (77%), feeling valuable (75%), patient feels more comfortable (62%). Patients (77%) reported feeling supported and more comfortable when a relative was present. Furthermore, patients felt less anxious (67%), experienced distraction (65%), and felt safer (69%).

Almost two-third of the patients (65%) reported higher levels (sometimes to always) of burden for their relatives. This is in line with half of the relatives (55%) reporting higher levels (sometimes to always) of emotional burden. Sixty-three percent of the relatives did not experience physical burden. When relatives experienced physical burden, emotional burden was also reported (52%). Sixty-three percent of the relatives took breaks 1-2 times a day, during which they left the patients' rooms. Nearly all relatives (98%) experienced sufficient attention from nurses.

Care delivery

Almost all relatives (90%) and patients (92%) reported higher levels (sometimes to always) of care involvement (Figure 2). Forty-six percent of the relatives assisted nurses in providing care for patients, and experienced adequate communication. All of the following tasks were mentioned by more than 50% of the participants: provide assistance in increasing mobility, going to the toilet, washing/getting dressed, helping with drinks and meals, and taking medication.

[Figure 2]

Sleep quality

More than a quarter of relatives (28%) reported poor sleep quality (mark <5.5) and identified factors such as hospital interruptions, staff members checking on patients, noise from medical equipment, an uncomfortable sofa bed and concerns about the patient. Almost two-third of the patients (61%) did not sleep well, but their sleep was not bad either, with a mean score of 6.3 (Figure 3 and Figure 4).

[Figure 3]

[Figure 4]

Overall experience

According to patients and relatives, care of rooming-in is well-organized. The following reasons were frequently reported by patients: feeling comfortable (84%), enjoying the

presence of a relative (71%) and feeling calmer (70%). Relatives reported the patient feeling better (87%) and calmer (77%), along with the relative's ability to give emotional support (79%), and provide information (77%). The experience with rooming-in was very good according to patients (80% \geq 8, median = 8, IQR = 8.0 to 9.0) and relatives (73% \geq 8, median = 8, IQR = 7.5 to 9.0). Only one patient gave a very low score (0) and wanted all meals available, clean linens and a better sofa bed for their relative. Three relatives gave a low score ($<$ 5.5), one of whom was the relative of the patient who gave a score of 0.

Participants provided suggestions for improvement and were centered on better communication. The top requests were for the hospital to provide clear information prior to or directly upon admission about drinks and meals, parking, and care delivery. Also more comfortable beds for relatives were suggested.

DISCUSSION

The findings of this study show the development of a 22-item patient-survey and 37-item relative-survey that are both considered content valid (S-CVI/Ave = 0.90 for both surveys) PROMs. In addition, this study found high satisfaction scores for rooming-in with patients and relatives.

In accordance with Polit and Beck²⁹, a higher standard for S-CVI/Ave than S-CVI/UA was demanded²⁹ and verified both surveys are content valid. It was not possible to compare these results with other studies because, to our knowledge, this is the first study that has developed questionnaires exploring rooming-in.

The findings from the second objective, describing rooming-in experiences using rooming-in surveys, are consistent with previous research that highlights family participation in care delivery^{1,3}. Most relatives performed care activities and had a favorable perception of their participation in care. In addition, patients and relatives appreciate the possibility of being together. Gasparini³ described that family presence reduces anxiety in relatives, thus increasing their perceptions of the quality of delivered care, and overall satisfaction³. Relatives want to be near loved ones during hospitalization and one way to increase participation is to include them in direct care^{1,13}. A relative's personal knowledge of the patient helps facilitate better nursing care because the relative can anticipate the patients' needs¹⁷. Involving relatives in patient care has a positive effect on self-management, patient outcomes, and quality of life for patients and relatives⁶. Although a low level of physical burden was reported in our study, relatives reported feeling emotionally burdened. Perhaps more admission days lead to a greater sense of burden. A previous study describes adverse effects that can occur when a relative is involved in care¹³. Relatives were exhausted, and it was difficult for them to be removed from their own routines at home where work and other family needs continue¹³.

Poor sleep quality was reported among relatives and is similar to results described by Buyn³¹. Poor sleep quality causes an impairment of daily activities. Symptoms of depression, anxiety, fatigue, as well as psychosocial distress and burden are associated with sleep disturbance in relatives³¹. As almost all relatives participated in care and described poor sleep quality, nurses should be aware of this burden upon relatives.

Communication among patients, relatives and staff was considered appropriate, and relatives were involved in care decisions. As decision-making is an important aspect of family participation, it is essential that patients and relatives receive information that is complete and accurate to make participation in care and decision-making effective¹. However, information about hospital's department rules was inadequate. Nurses should have a key-advocate role in promoting relatives in care processes, expressing expectations to those concerned, and guiding relatives during rooming-in following standard procedures^{6,13,17}.

Our study has several strengths. First, prior to the administration of surveys, an extensive validation process on content took place. Content validity is the most important measurement property of a PROM, and also the most challenging to assess²². Second, a pilot was conducted prior to the administration of these surveys. Third, these surveys are, to our knowledge, the first to assess rooming-in experiences of adult inpatients and their relatives, and makes it possible to obtain quantified data.

Several potential limitations should be mentioned. First, selection bias must be taken into account because severely ill patients and their relatives were not asked to participate. Second, socially desirable answers may have been given, especially when the researcher filled out surveys together with participants due to language barriers, low vision, disability, and other physical limitations. However, telling participants that surveys were treated confidentially was considered to be helpful in decreasing socially desirable answers. Third, Polit and Beck²⁴ recommend two rounds of relevance assessment for content validity²⁹. S-CVI was recalculated after modifying items after the first review. Finally, generalization may be limited because the study was performed in a single center using a relatively small sample. However, the sample size was reached, thus indicating good methodological quality.

Some items may be evaluated in future studies and may have to be modified or removed before using these surveys in other hospitals. To improve communication about general rules in a department, rooming-in guidelines should be developed to provide guidance for patients and their relatives. A growing number of hospitals are adopting policies that align with the PFCC approach. Because nurses are the ones who have the most contact with patients and relatives, these professionals should be involved in implementing rooming-in procedures. In addition, more comfortable sofa beds are recommended to increase sleep quality of relatives.

In conclusion, two content valid surveys were developed that assess rooming-in experiences of hospitalized adult patients and their relatives during hospital admission. Rooming-in experiences were very good, and patients and relatives appreciated the possibility of being together for 24 hours a day. Clear information about healthcare policies is essential to improve patient- and relative satisfaction, guarantee continuity of care, and increase quality of care.

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TABLES AND FIGURES

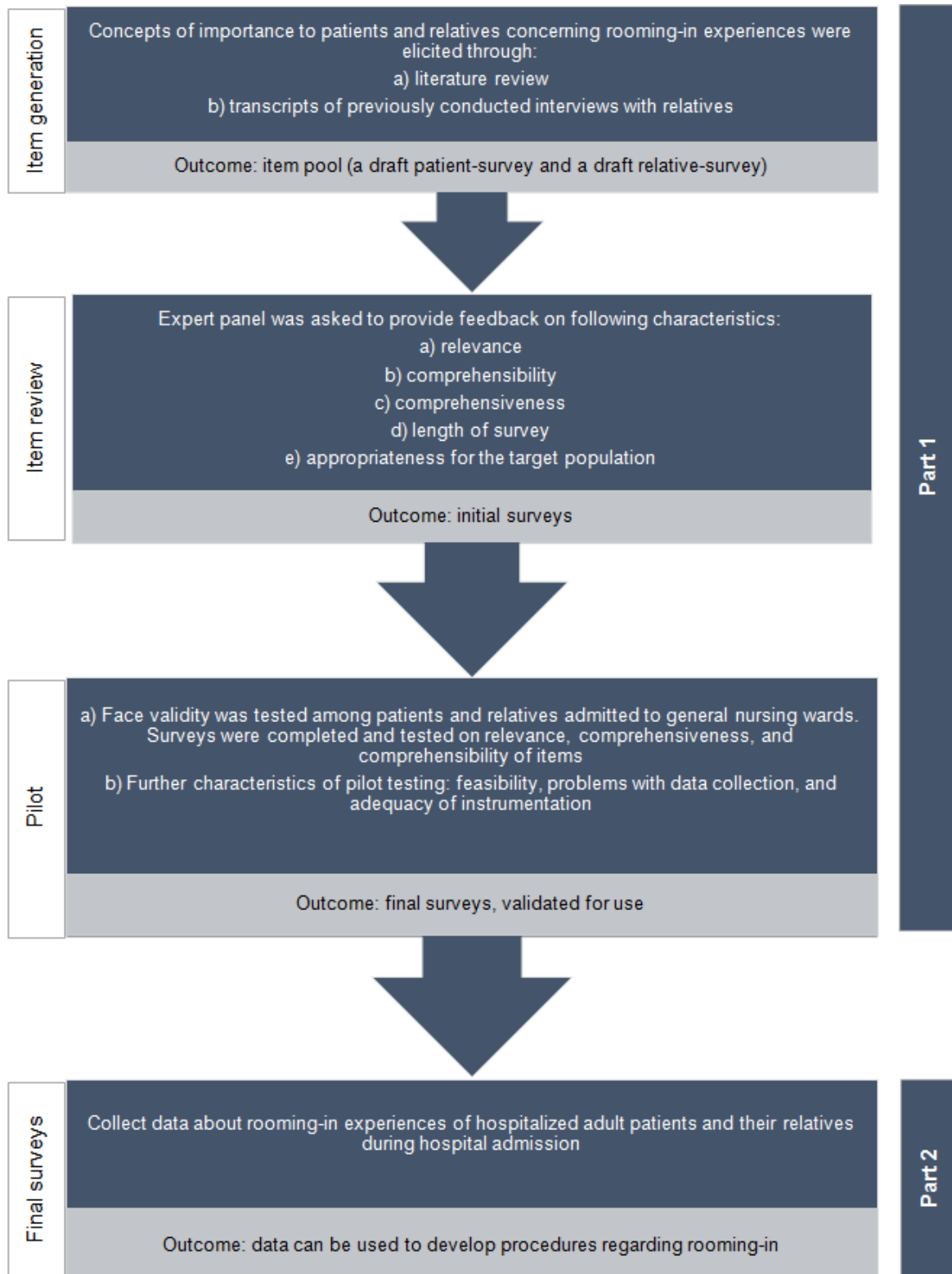


Figure 1. Flowchart of the stud

Table 1. Content validity index patient-survey

Items	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Expert 6	Expert 7	Expert 8	Expert 9	Experts in agreement	I-CVI	After revision of items
1	4	3	3	4	4	4	2	3	4	8	0,89	Removed
2	3	3	4	4	4	4	3	3	4	9	1	Removed
3	3	3	3	3	2	3	2	2	3	6	0,67	Removed
4	4	4	4	3	4	3	3	3	1	8	0,89	Removed
5	4	3	4	4	4	3	3	3	4	9	1,00	
6	3	2	3	4	3	2	3	3	4	7	0,78	
7	4	2	4	4	4	3	4	3	4	8	0,89	
8	2	3	3	4	4	3	3	2	4	7	0,78	
9	3	4	4	4	4	4	3	3	4	9	1,00	
10	2	2	4	3	4	3	3	3	4	7	0,78	
11	4	4	4	4	4	4	3	2	4	8	0,89	
12	4	3	4	4	4	4	3	3	4	9	1,00	
13	2	2	3	4	3	3	3	2	3	6	0,67	Removed
14	2	4	4	4	4	3	3	2	4	7	0,78	
15	3	4	3	2	4	3	4	3	4	8	0,89	Removed
16	4	2	3	4	4	3	3	3	4	8	0,89	Removed
17	4	3	3	3	4	3	3	3	3	9	1,00	Removed
18	4	4	4	4	4	3	4	1	4	8	0,89	
19	4	4	4	4	4	2	3	1	4	7	0,78	
20	4	3	4	3	4	3	3	3	4	9	1,00	
21	4	4	4	4	4	3	4	3	1	8	0,89	
22	3	4	3	4	4	2	2	3	4	7	0,78	Removed
23	3	2	3	4	4	2	2	3	4	6	0,67	Removed
24	3	2	3	4	1	2	2	1	4	4	0,44	Removed

25	3	2	3	4	4	2	2	3	4	6	0,67	Removed
26	3	2	3	4	4	2	2	3	4	6	0,67	Removed
27	3	2	3	4	4	2	2	3	4	6	0,67	Removed
28	3	4	4	4	4	2	3	2	4	7	0,78	Removed
29	3	4	4	4	4	2	3	2	4	7	0,78	Removed
30	3	4	3	4	4	3	3	3	4	9	1,00	Removed
31	3	4	4	4	4	3	3	2	4	8	0,89	
32	3	4	4	4	4	4	3	3	4	9	1,00	Removed
33	1	4	4	4	4	1	3	2	4	6	0,67	Removed
34	3	4	4	4	4	3	3	1	4	8	0,89	Removed
35	4	4	4	4	4	4	3	1	4	8	0,89	
36	3	4	4	4	4	3	3	3	4	9	1,00	
37	4	4	4	4	4	3	3	3	4	9	1,00	Removed
38	4	4	4	4	4	3	3	3	4	9	1,00	
										S-CVI/Ave	0,85	0,90
										Total	11	6
										agreement		
										S-CVI/UA	0,29	0,38

I-CVI = item-level content validity index (cut-off = 0.78); S-CVI/UA = scale-level content validity index, universal agreement method (cut-off = 0.80); S-CVI/Ave = scale-level content validity index, averaging method (cut-off = 0.90)

Table 2. Content validity index relative-survey

Items	Expert 1	Expert 2	Expert 3	Expert 4)	Expert 5	Expert 6	Expert 7	Expert 8	Expert 9	Number agreement	I-CVI	Revision of items
1	4	4	4	4	4	3	3	3	4	9	1,00	Removed
2	3	4	4	4	4	3	3	3	4	9	1,00	Removed
3	3	2	2	2	2	3	2	2	4	3	0,33	Removed
4	4	1	1	2	4	3	2	3	1	4	0,44	Removed
5	4	4	4	4	4	3	4	3	4	9	1,00	
6	4	4	4	4	4	3	4	3	4	9	1,00	
7	3	3	4	4	4	4	2	3	4	8	0,89	Removed
8	3	3	4	4	4	3	4		4	8	1,00	
9	3	4	4	4	4	1	3	3	4	8	0,89	
10	2	3	4	4	4	3	3	2	4	7	0,78	
11	3	4	2	4	1	1	1		4	4	0,50	
12	3	4	4	4	4	3	3	3	4	9	1,00	
13	2	3	4	4	4	3	3	3	4	8	0,89	
14	4	4	4	4	4	2	3	2	4	7	0,78	
15	4	4	4	4	4	3	3	3	4	9	1,00	
16a	1	4	3	4	4	3	2	3	4	7	0,78	
16b	3	3	4	4	4	3	2	3	4	8	0,89	
16c	3	3	4	4	4	3	2	3	4	8	0,89	
16d	3	3	4	4	1	3	2	1	4	6	0,67	Removed
17	3	3	4	2	4	3	2		4	6	0,75	Removed
18	2	2	4	4	3	3	2	2	3	5	0,56	Removed
19	2	4	4	4	4	3	3	2	4	7	0,78	
20	3	4	4	2	4	3	3	3	4	8	0,89	Removed
21	4	4	4	4	4	4	3	3	4	9	1,00	

22	4	4	4	4	4	3	3	2	4	8	0,89	
23	4	4	4	4	4	3	2	2	4	7	0,78	
24	4	4	4	3	4	3	2	2	4	7	0,78	
25	4	4	4	4	4	3	3	3	4	9	1,00	Removed
26	3	4	4	4	4	3	3	2	4	8	0,89	
27	4	4	4	4	4	4	3	1	4	8	0,89	
28	4	4	4	4	4	3	3	2	3	8	0,89	
29	4	4	4	4	4	3	3	3	4	9	1,00	
30	4	4	4	4	4	3	3	3	4	9	1,00	
31	3	4	4	3	4	3	2	3	4	8	0,89	
32	4	4	4	4	4	3	3	3	4	9	1,00	
33	4	3	4	4	4	4	3	3	4	9	1,00	
34	4	4	4	3	4	4	2	3	4	8	0,89	Removed
35	3	4	4	4	4	3	3	1	4	8	0,89	
36	3	2	4	4	4	3	3	2	4	7	0,78	
37	3	2	4	4	4	3	3	3	4	8	0,89	Removed
38	3	2	4	4	4	3	2	3	4	7	0,78	Removed
39	3	2	2	4	1	3	2	1	4	4	0,44	Removed
40	3	2	2	4	4	3	2	3	4	6	0,67	Removed
41	3	2	2	4	4	3	3	3	4	7	0,78	Removed
42	3	2	4	4	4	3	2	3	4	7	0,78	Removed
43	3	4	4	3	4	2	3	2	4	7	0,78	Removed
44	3	4	4	3	4	2	3	3	4	8	0,89	Removed
45	3	4	4	4	4	3	3	3	4	9	1,00	
46	3	4	4	4	4	3	3	3	4	9	1,00	
47	1	4	4	4	4	3	3	2	4	7	0,78	Removed
48	3	4	4	4	4	3	3	3	4	9	1,00	Removed

49	3	4	4	4	4	3	3	2	4	8	0,89	
50	3	4	4	4	4	3	3	3	4	9	1,00	Removed
51	3	4	4	4	4	3	3	1	4	8	0,89	
52	4	4	4	4	4	3	3	1	2	7	0,78	
53	3	4	4	4	4	3	3	3	4	9	1,00	
54	4	4	4	4	4	3	3	3	4	9	1,00	Removed
55	4	4	4	4	4	3	3	3	4	9	1,00	
										S-CVI/Ave	0,85	0,90
										Total agreement	19	13
										S-CVI/UA	0,35	0,37

I-CVI = item-level content validity index (cut-off = 0.78); S-CVI/UA = scale-level content validity index, universal agreement method (cut-off = 0.80); S-CVI/Ave = scale-level content validity index, averaging method (cut-off = 0.90)

Table 3. Baseline characteristics of patients (n=51)

Variables	Total population (n= 51)
Gender	
Male	26 (51%)
Female	25 (49%)
Age, years	
Mean; SD	55.9; (18.4)
Relationship towards relative	
Spouse/partner	36 (70.6%)
Parent/guardian	7 (13.7%)
Daughter/son	6 (11.8%)
Nephew	1 (2%)
Sister in law	1 (2%)
Specialism	
Cardiology	9 (17.6%)
Internal oncology	8 (15.7%)
Gastro-intestinal surgery	6 (11.8%)
Oncologic surgery	4 (7.8%)
Gastroenterology and Hepatology (MDL)	3 (5.9%)
Neurosurgery	3 (5.9%)
Vascular surgery	3 (5.9%)
Cardiothoracic surgery	3 (5.9%)
Urology	2 (3.9%)
Haematology	2 (3.9%)
Gynaecology	2 (3.9%)
Immunology	2 (3.9%)
Ear Nose Throat (ENT)	2 (3.9%)
Transplantation surgery	1 (2.0%)
Internal medicine	1 (2.0%)
Admission days	
Median; min-max	5; 2-91
First time rooming-in	
Yes	37 (72.5%)
No	14 (27.5%)
If no*,	10 (mean 4.8; SD 5.6)
*Missing	4
EQ-5D	
Mobility	50 (Mean 1.9; SD 0.7)

Self-care	51 (Mean 2.0; SD 0.7)
Usual activities	51 (Mean 2.2; SD 0.7)
Pain/discomfort	51 (Mean 2.0; SD 0.6)
Anxiety/depression	51 (Mean 1.6; SD 0.6)
General state of health	50 (Mean 62.3; SD 18.9)

Table 4. Baseline characteristics of relatives (n=60)

Variables	Total population (n= 60)
Gender	
Male	17 (28.3%)
Female	43 (71.7%)
Age, years	
Mean	Between 41-55 years
≤ 25 years	3 (5%)
26 – 40 years	10 (16.7%)
41 – 55 years	21 (35%)
56 – 70 years	20 (33.3%)
> 71 years	6 (10%)
Relation to patient	
Spouse/partner	39 (65%)
Parent/guardian	7 (11.7%)
Daughter/son	10 (16.7%)
Siblings	0 (0%)
Uncle	1 (1.7%)
Mother in law	1 (1.7%)
Son in law	1 (1.7%)
Sister in law	1 (1.7%)
Specialism	
Cardiology	10 (16.7%)
Internal oncology	9 (15%)
Gastro-intestinal surgery	6 (10%)
Oncologic surgery	4 (6.7%)
Vascular surgery	4 (6.7%)
Neurosurgery	3 (5%)
Gastroenterology and Hepatology (MDL)	3 (5%)
Cardiothoracic surgery	3 (5%)
Immunology	3 (5%)
Urology	2 (3.3%)
Haematology	2 (3.3%)
Gynaecology	2 (3.3%)
Ear Nose Throat (ENT)	2 (3.3%)
Internal medicine	2 (3.3%)
Geriatric department	2 (3.3%)
Endocrinology	1 (1.7%)

Transplantation surgery	1 (1.7%)
Nephrology	1 (1.7%)
Number of days rooming-in	
Median, min-max	3; 1-91 days
First time rooming-in	
Yes	44 (73.3%)
No	16 (26.7%)
If no,*	11 (mean 1.6; SD 1.0)
*Missing	5
Primary contact person	
Yes	51 (85%)
No	9 (15%)
Travel distance	
0-29 minutes	17 (29.3%)
30-59 minutes	17 (29.3%)
60-89 minutes	9 (15.5%)
90 – 120 minutes	12 (20.7%)
>120 minutes	3 (5%)
Missing	2 (2.3%)

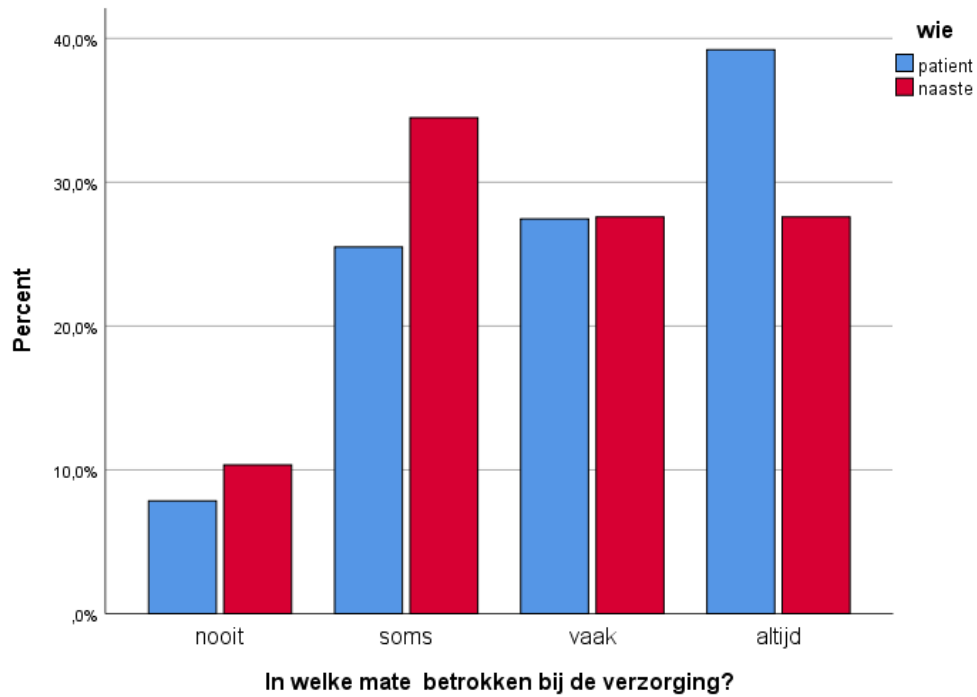


Figure 2. Involvement in care (patients and relatives)

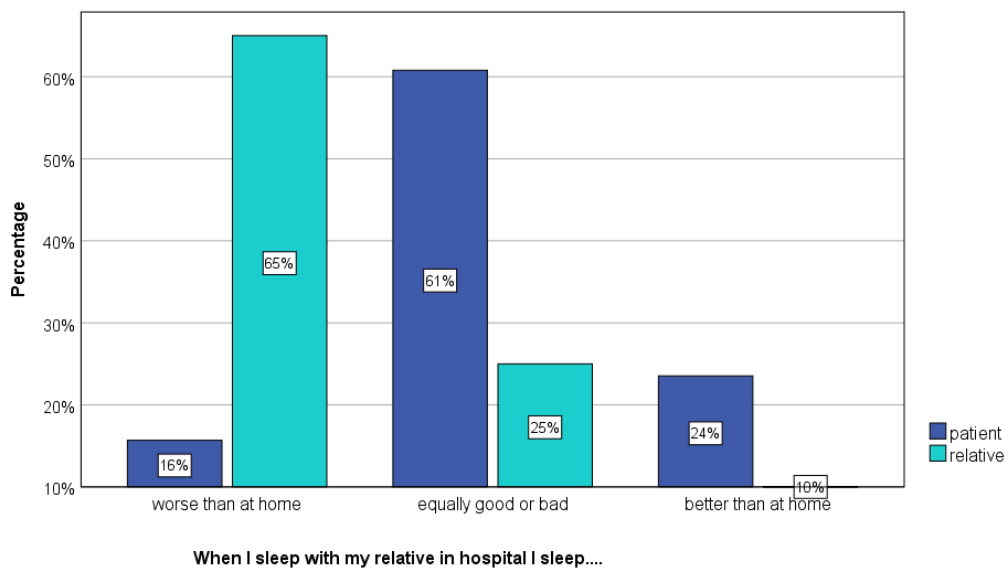


Figure 3. Sleep quality of patients and relatives

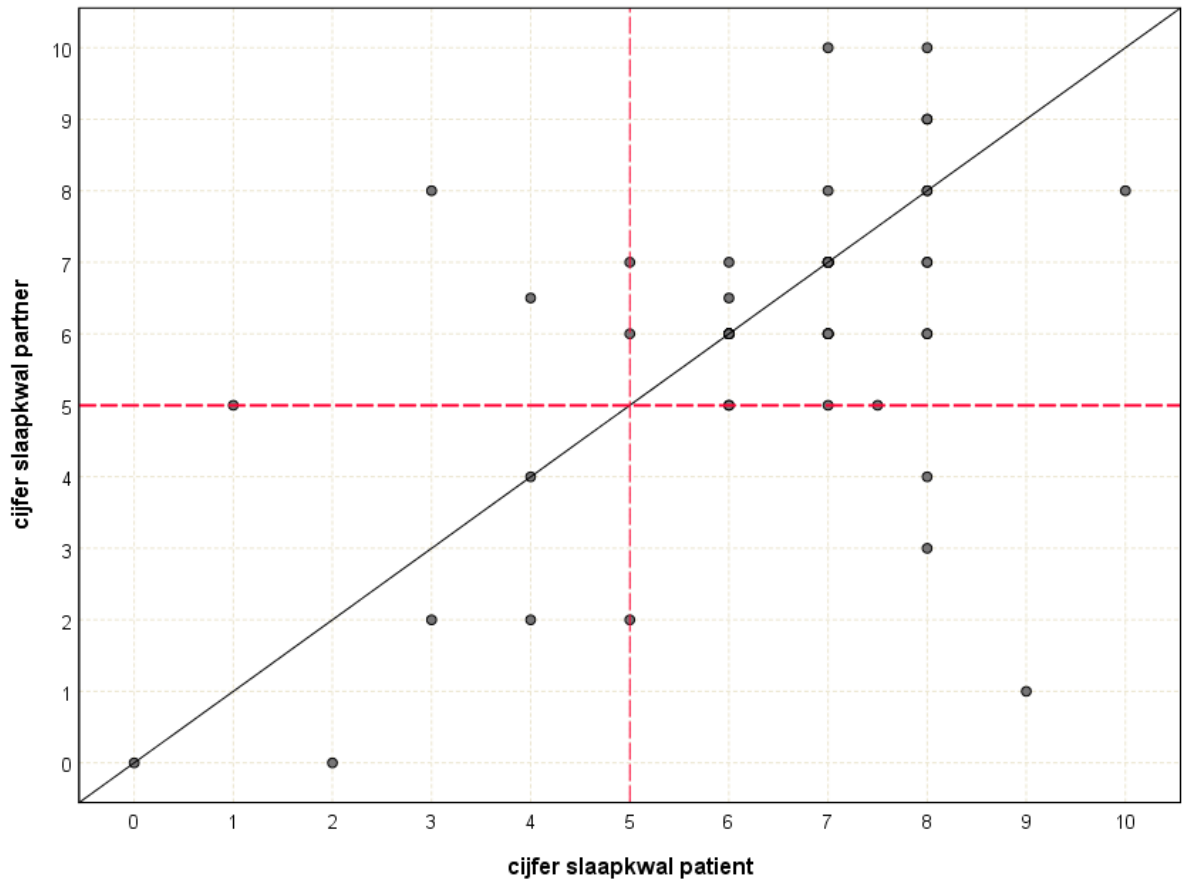


Figure 4. Scores sleep quality of patients and relatives

APPENDICES

APPENDIX 1: Development process patient-survey

Item generation – first review experts

Draft survey (item generation)	Comments/advice in first review by expert panel	Survey after first review by expert panel (item review)
Question 1 (gender)	Not relevant, information can be provided from EPD	Removed
Question 2 (age)	Not relevant, information can be provided from EPD	Removed
Question 3 (marital status)	Not relevant to assess rooming-in	Removed
Question 4 (having children)	Not relevant	Removed
Question 5 (relation to relative)	Revised question for clarity	Question 4
Question 6 (admission days)	Revised question for clarity	Question 1
Question 7 (reason for admission)		Question 5
Question 8 (first time rooming-in)	Revised question for clarity and completeness	Question 2
Question 9 (when relative present)	Revised question + response option (multiple responses)	Question 3
Question 10 (other relatives rooming-in)	Revised question + response option for completeness	Question 7
Question 11 (practical aspects)	Revised question + response option for clarity	Question 8
Question 12 (practical aspects)	Revised question + response option for clarity and completeness	Question 9
Question 13 (psychosocial well-being)	Not relevant according to CVI	Removed
Question 14 (psychosocial well-being)	Revised question + response option	Question 10
Question 15 (psychosocial well-being)	Combine with other questions	Removed
Question 16 (psychosocial well-being)	Not clear and complete	Removed
Question 17 (care delivery)	Not clear	Removed

Question 18 (care delivery)	Merged with questions 14 and 15. Revised question + response option for clarity	Merged
Question 19 (care delivery)	Merged with question 14	Merged
Question 20 (psychosocial well-being)		Question 12
Question 21 (psychosocial well-being)		Removed
Question 22 (sleep quality)	Too many questions about sleep, merge	Removed
Question 23 (sleep quality)	Too many questions about sleep, merge	Removed
Question 24 (sleep quality)	Too many questions about sleep, merge	Removed
Question 25 (sleep quality)	Too many questions about sleep, merge	Removed
Question 26 (sleep quality)	Too many questions about sleep, merge	Removed
Question 27 (sleep quality)	Too many questions about sleep, merge	Removed
Question 28 (communication)	Question is too general	Removed
Question 29 (communication)	Question is too general	Removed
Question 30 (communication)	Question is not clear and relevant. Make a distinction between active and passive communication	Removed
Question 31 (practical aspects)	Revised question + response option because added value is not clear	Question 17
Question 32 (communication)	Not relevant	Removed
Question 33 (communication)	Not relevant and clear	Removed
Question 34 (communication)	Question is not relevant for patient, only for relative	Removed
Question 35 (care delivery)	Revised question + response option because question is not complete. Multiple responses added	Question 18
Question 36 (practical aspects)		Question 19
Question 37 (practical aspects)	Not relevant because rooming-in is only applied when indicated	Removed
Question 38 (practical aspects)		Question 20
Additional questions added:		

Question 6 = Background information (Is your relative primary contact person?)

Question 11 = Psychosocial well-being (Because of rooming in)

Question 13 = Care delivery (To what extent is your relative involved in care?)

Question 16 = Sleep quality (How do you rate your sleep last night?)

Second review experts – pilot

Survey before the second review by expert panel (item review)	Comments/advice in second review	Survey for pilot (pilot testing)	Comments/advice in pilot
Question 1		Question 1	
Question 2		Question 2	Remove 'during this admission' for clarity
Question 3		Question 3	
Question 4	Add response option 'guardian' for completeness	Question 4	
Question 5		Question 5	
Question 6		Question 6	
Question 7		Question 7	
	Add question about practical aspects 'Who told you rooming-in is possible?'	Question 8	Add 'told me' and 'told me after I requested' for clarity
Question 8		Question 9	
Question 9	Add response option 'Participate or take over care' for completeness	Question 10	Revise first response option for clarity
Question 10		Question 11	Switch response options to positive (totally agree) to negative (totally disagree) instead of the other way around
Question 11		Question 12	
Question 12		Question 13	
Question 13	Add instruction for clarity	Question 14	
Question 14		Question 15	
Question 15		Question 16	

	Add question about sleep 'When I sleep in the hospital I sleep....'	Question 17	
Question 16		Question 18	Revise question somehow to make more clear patients need to rate
Question 17		Question 19	
Question 18		Question 20	
Question 19		Question 21	
Question 20		Question 22	

APPENDIX 2: CONCEPTS AND ITEMS FOR PATIENT- AND RELATIVE-SURVEY

Background information

Reason rooming in/Travel distance /Relationship towards patient (spouse, adult child etc)
/Date of admission /Date start rooming in/ Date questionnaire / first time rooming in / working status / having a family/EQ-5D for patients

1. Practicalities

- Departmental rules clear?
- Agreement with rules?
- Facilities

2. Burden/relief/(feeling guilty = for patients)

- Financial burden? (Food and beverages parking costs, financial situation difficult etc)
- Emotional burden (being together so often, seeing suffering, energy)
- Sense of altruism (happy to be able to do this)
- Taking time for relaxation or not (How often away from room/department?)
- Being away from home
- Being away from other family members
- Lack of sleep?

3. Communication

- Communication with nurses
- Communication with patient
- Communication with medical doctors

APPENDIX 3: Development process relative-survey

Item generation – first review experts

Draft questionnaire (item generation)	Comments/advice in first review by expert panel	Questionnaire after first review by expert panel (item review)
Question 1 (gender)	Not relevant, information can be provided by EPD	Removed
Question 2 (age)	Not relevant, information can be provided by EPD	Removed
Question 3 (marital status)	Based on CVI	Removed
Question 4 (having children)	Based on CVI	Removed
Question 5 (relation to patient)	Revised question for clarity	Question 5
Question 6 (reason rooming-in)	Revised response options (multiple choice question for completeness)	Question 6
Question 7 (work status)	Not relevant	Removed
Question 8 (travel distance)		Question 10
Question 9 (admission days patient)		Question 1
Question 10 (first time rooming-in)	Revised question for clarity	Question 3
Question 11 (when started)	Revised question (not removed although low CVI) because researchers valued question as important	Question 2
Question 12 (when present)	Revised response options	Question 4
Question 13 (other relatives present)	Revised question and response option for clarity	Question 8
Question 14 (practical aspects)	Revised question and response option for clarity	Question 11

Question 15 (practical aspects)	Revised question and response option for clarity	Question 12
Question 16 (practical aspects)	Question merged with question 12	Merged
Question 17 (practical aspects)	Not relevant	Removed
Question 18 (psychosocial well-being)	Based on CVI	Removed
Question 19 (psychosocial well-being)	Revised question and response option for clarity	Question 15
Question 20 (psychosocial well-being)	Question can be merged with other questions	Removed
Question 21 (psychosocial well-being)	Revised question for clarity	Question 17
Question 22 (psychosocial well-being)	Question merged with question 19	Merged
Question 23 (care delivery)	Question merged with question 19	Merged
Question 24 (care delivery)	Question merged with question 19	Merged
Question 25 (psychosocial well-being)	Removed Partly merged with question 15	
Question 26 (psychosocial well-being)		Question 16
Question 27 (physical well-being)	Question merged with question 19	Merged
Question 28 (care delivery)	Revised question and response option for clarity	Question 21
Question 29 (physical well-being)	Revised question and response option for clarity. Examples added (pain, fatigue)	Question 22
Question 30 (leisure)	Revised response options (revised answer categories)	Question 24 (Merged)

Question 31 (leisure)	Revised response options (added answer categories)	Question 24 (Merged)
Question 32 (leisure)	Revised question for clarity	Question 23
Question 33 (leisure)		Question 25
Question 34 (leisure)		Removed
Question 35 (financial aspects)	Revised question and response option for clarity	Question 26 (Merged)
Question 36 (financial aspects)	Revised question and response option for clarity	Question 26 (Merged)
Question 37 (sleep quality)	Ask one global question about sleep	Removed, question 27
Question 38 (sleep quality)	Ask one global question about sleep	Removed, question 27
Question 39 (sleep quality)	Ask one global question about sleep	Removed, question 27
Question 40 (sleep quality)	Ask one global question about sleep	Removed, question 27
Question 41 (sleep quality)	Ask one global question about sleep	Removed, question 27
Question 42 (sleep quality)	Ask one global question about sleep	Removed, question 27
Question 43 (communication)	Question is to general	Removed
Question 44 (communication)	Question is to general	Removed
Question 45 (communication)	Revised question and response option for clarity	Question 28
Question 46 (communication)		Question 29
Question 47 (communication)	Not relevant; too many questions about this aspect	Removed
Question 48 (communication)	Not relevant; too many questions about this aspect	Removed
Question 49 (practical aspects)	Revised response options	Question 31
Question 50 (communication)	Not relevant	Removed
Question 51 (communication)		Question 32

Question 52 (care delivery)	Revised question and response option for clarity (added multiple choices)	Question 33
Question 53 (practical aspects)		Question 34
Question 54 (practical aspects)	Not relevant. Rooming-in is only provide when indicated	Removed
Question 55 (practical aspects)		Question 35

Additional questions added:

Question 7 = Background information (Are you primary contact person?)

Question 9 = Practical aspects (Do you have obligations that take time?)

Question 13 = Practical aspects (Did you have to arrange matters to make rooming-in possible?)

Question 14 = Psychosocial well-being (Because of rooming-in)

Question 18 = Care delivery (To what extent are you involved in care?)

Question 20 = Care delivery (If you take care, what tasks do you provide?)

Question 30 = Care delivery (Do you think nursing staff works differently when you are present in the patient room?)

Second review experts – pilot

Questionnaire before the second review by expert panel (item review)	Comments/advice in second review	Questionnaire for pilot (pilot testing)	Comments/advice in pilot
Question 1	Same as question 2	Removed	
Question 2		Question 1	
Question 3		Question 2	Remove 'during admission' for clarity
Question 4		Question 3	
Question 5	Add response option 'Guardian'	Question 4	
Question 6		Question 5	
Question 7		Question 6	
Question 8		Question 7	
Question 9	Add response option 'Care for children'	Question 8	Add response option 'not applicable'
Question 10	Revised question	Question 9	
	Add question	Question 10	Add information to response options for clarity
Question 11		Question 11	
Question 12	Revised question; add 'physicians' and add an response option 'participate or take over care'	Question 12	
Question 13		Question 13	Revise term 'furniture' for clarity
Question 14	Revised response option	Question 14	
Question 15		Question 15	Switch response options to positive (totally agree) to negative (totally disagree) instead of the other way around
Question 16		Question 16	Revise response options from yes/no to never, sometimes, often, always

Question 17		Question 17
Question 18	Add a description	Question 18
Question 19		Question 19
Question 20		Question 20
Question 21		Question 21
Question 22		Question 22
Question 23		Question 23
Question 24		Question 24
Question 25		Question 25
Question 26	Revised response options 'No' and 'I save costs'	Question 26
	Add question about sleep	Question 27
Question 27		Question 28
		Revise question somehow to make more clear patients need to rate
Question 28		Question 29
Question 29		Question 30
Question 30	Revised response options in 'Yes, because...', 'No, because...' and 'I don't know'	Question 31
Question 31		Question 32
Question 32		Question 33
Question 33	Add response option 'I am here to provide emotional support'	Question 34
Question 34		Question 35
Question 35		Question 36

Add one question about the age of relatives
→ will be question 1 in final questionnaire

APPENDIX 4: final patient-survey

Rooming-in

In het Erasmus Medisch Centrum is het mogelijk dat iemand de gehele dag bij een patiënt op de kamer verblijft en mag blijven slapen. Dit wordt rooming-in genoemd. U ontvangt deze vragenlijst omdat er een naaste bij u in het ziekenhuis aanwezig is. Wij zijn benieuwd hoe u dit vindt. Met uw mening en de mening van anderen kunnen we rooming-in zo nodig verbeteren.

Rooming-in wordt officieel als volgt omschreven:

De patiënt de mogelijkheid bieden om tijdens een ziekenhuisopname 24 uur per dag een naaste in zijn/ haar patiëntenkamer te kunnen ontvangen inclusief overnachting op de kamer

Eerst vragen we persoonlijke informatie. Daarna volgen uitspraken over praktische, emotionele en lichamelijke zaken, en hoe u het contact met artsen en verpleegkundigen ervaart.

In de vragenlijst wordt met 'naaste' een persoon uit uw nabije omgeving bedoeld. Dit kan een partner, ouder, kind, familielid of ander voor u belangrijk persoon zijn die bij u aanwezig is in het ziekenhuis.

Zet bij iedere uitspraak een kruisje in het hokje dat het beste past. Soms zijn er meerdere antwoorden mogelijk. Dit is dan duidelijk aangegeven. Het invullen van de vragenlijst duurt 15 tot 20 minuten.

1. Hoeveel nachten bent u nu al opgenomen tijdens deze opname?

--

2. Is dit de eerste keer dat er iemand in het ziekenhuis bij u blijft slapen?

- Ja
- Nee
 - o Zo nee, hoe vaak is iemand blijven slapen?

3. Wanneer is uw naaste aanwezig?

(meerdere antwoorden mogelijk)

- In de ochtend
- In de middag
- In de avond
- In de nacht
- 24 uur per dag

4. Wat is uw relatie tot uw naaste die op dit moment bij u verblijft?

- Echtgenoot/echtgenote/partner
- Ouder/voogd
- Dochter/zoon
- Broer/zus
- Anders, namelijk.....

5. Om welke reden is uw naaste aanwezig?

(meerdere antwoorden mogelijk)

- Omdat ik angstig ben
- Omdat mijn naaste helpt bij de verzorging
- Omdat ik me onrustig voel
- Omdat mijn naaste dan minder hoeft te reizen
- Omdat ik weinig of geen Nederlands spreek
- Anders, namelijk

6. Is de naaste die momenteel bij u aanwezig is ook de eerste contactpersoon?

- Ja

- Nee
7. Is er weleens iemand anders blijven slapen tijdens deze ziekenhuisopname?
- Ja, namelijk..... (relatie benoemen)
 - Nee
 - Er verblijven afwisselend andere naasten
8. Wie heeft u verteld dat rooming-in mogelijk is?
- Mijn naaste
 - De verpleegkundige heeft het verteld
 - De verpleegkundige heeft het verteld nadat ik erom heb gevraagd
 - De arts
9. Wanneer werd u verteld dat rooming-in mogelijk is?
- Op het moment dat ik werd opgenomen op de afdeling
 - Op het moment dat mijn situatie wijzigde
 - Ik ben er zelf over begonnen
 - Anders, namelijk.....
10. Welke afspraken hebben artsen en verpleegkundigen gemaakt over rooming-in?
(meerdere antwoorden mogelijk)
- Over tijdstip in- en uitschuiven en opmaken van het bedmeubel
 - Over drink- en maaltijdvoorziening
 - Over bezoek andere naasten
 - Over bijwonen artsenvisite
 - Over deelnemen of overnemen van de verzorging
 - Anders, namelijk.....
 - Er zijn geen afspraken gemaakt
11. Ik vind het fijn dat mijn naaste de mogelijkheid heeft om de gehele dag aanwezig te zijn
- Helemaal mee eens
 - Mee eens
 - Niet mee eens, niet mee oneens
 - Mee oneens
 - Helemaal mee oneens
12. Door rooming-in:
(meerdere antwoorden mogelijk)

- Voel ik me veilig
- Ervaar ik steun
- Heb ik afleiding
- Voel ik me meer ontspannen
- Ben ik minder angstig
- Anders, namelijk.....

13. Ik heb het gevoel dat mijn naaste belast wordt door rooming-in

- Nooit
- Soms
- Vaak
- Altijd

14. In welke mate wordt uw naaste betrokken bij uw verzorging? *(bijvoorbeeld helpen bij wassen/aankleden/naar de wc gaan; helpen bij eten, bewegen, innemen van medicijnen, activiteiten ondernemen)*

- Nooit
- Soms
- Vaak
- Altijd

15. Als de verpleegkundige mij komt verzorgen *(bijvoorbeeld helpen bij wassen/aankleden/naar de wc gaan; helpen bij eten, bewegen, innemen van medicijnen, activiteiten ondernemen)*, dan:

- Gaat mijn naaste meestal van de kamer af
- Blijft mijn naaste meestal op de kamer en laat de verpleegkundige het werk doen
- Blijft mijn naaste op de kamer en helpt de verpleegkundige
- Blijft mijn naaste op de kamer en doet de verzorging zonder hulp van de verpleegkundige

16. Indien uw naaste taken overneemt, welke zijn dit dan?

(meerdere antwoorden mogelijk)

- Hulp bij wassen en aankleden
- Hulp bij naar de wc gaan
- Hulp bij het eten en drinken
- Hulp bij uit bed komen, lopen etc.
- Hulp bij innemen medicatie
- Hulp anders, te weten.....
- Niet van toepassing

17. Als mijn naaste in het ziekenhuis blijft slapen, dan slaap ik:

- Beter dan thuis, omdat.....
- Slechter dan thuis, omdat.....
- Even goed of slecht als thuis

18. Wat voor rapportcijfer geeft u uw slaap de afgelopen nacht? *Erg slechtgeslapen* (0)
_____ *uitstekend geslapen* (10)

19. Mijn naaste blijft aanwezig op de kamer tijdens de doktersvisite

- Nooit
- Soms
- Vaak
- Altijd
- Niet van toepassing omdat mijn naaste niet de eerste/tweede contactpersoon is

20. Door rooming-in heb ik het gevoel dat er goed voor mij wordt gezorgd, omdat:
(meerdere antwoorden mogelijk)

- Mijn naaste aanwezig is
- Mijn naaste informatie kan geven
- Ik me prettiger voel omdat mijn naaste mag overnachten
- Mijn naaste mag helpen bij de verzorging
- Mijn naaste ervoor zorgt dat ik meer kan bewegen
- Ik me meer ontspannen en rustiger voel
- Anders, namelijk.....

21. Mijn algemene ervaring met rooming-in zou ik beschrijven als *erg slecht* (0)
_____ *uitstekend* (10)

22. Wat zou u het Erasmus MC willen adviseren om rooming-in te verbeteren?

Bedankt voor uw deelname!

APPENDIX 5: final relative-survey

Rooming-in

In het Erasmus Medisch Centrum is het mogelijk dat iemand de gehele dag bij een patiënt op de kamer verblijft en mag blijven slapen. Dit wordt rooming-in genoemd. U ontvangt deze vragenlijst omdat u bij uw naaste in het ziekenhuis aanwezig bent. Wij zijn benieuwd hoe u dit vindt. Met uw mening en de mening van anderen kunnen we rooming-in zo nodig verbeteren.

Rooming-in wordt officieel als volgt omschreven:

De patiënt de mogelijkheid bieden om tijdens een ziekenhuisopname 24 uur per dag een naaste in zijn/ haar patiëntenkamer te kunnen ontvangen inclusief overnachting op de kamer

Eerst vragen we persoonlijke informatie. Daarna volgen uitspraken over praktische, financiële, emotionele en lichamelijke zaken, en hoe u het contact met artsen en verpleegkundigen ervaart. In de vragenlijst wordt over 'naaste' gesproken en hiermee wordt de patiënt bedoeld.

Zet bij iedere uitspraak een kruisje in het hokje dat het beste past. Soms zijn er meerdere antwoorden mogelijk. Dit is dan duidelijk aangegeven. Het invullen van de vragenlijst duurt 20 tot 25 minuten.

1. Hoeveel nachten bent u nu al bij uw naaste aanwezig tijdens deze opname?

2. Is dit de eerste keer dat u in het ziekenhuis bij uw naaste blijft slapen?

- Ja
- Nee
 - Zo nee, hoe vaak bent u blijven slapen?

3. Wanneer bent u aanwezig bij uw naaste?

(meerdere antwoorden mogelijk)

- In de ochtend
- In de middag
- In de avond
- In de nacht
- 24 uur per dag

4. Wat is uw relatie tot uw naaste die op dit moment bij u verblijft?

- Echtgenoot/echtgenote/partner
- Ouder/voogd
- Dochter/zoon
- Broer/zus
- Anders, namelijk.....

5. Wat is uw leeftijd?

- Jonger dan 25 jaar
- 26 – 40 jaar
- 41 – 55 jaar
- 56 – 70 jaar
- 71 jaar of ouder
- Dat wil ik niet zeggen

6. Om welke reden bent u aanwezig bij uw naaste?

(meerdere antwoorden mogelijk)

- Omdat mijn naaste angstig is
- Omdat ik help bij de verzorging
- Omdat mijn naaste onrustig is

- Omdat ik dan minder hoef te reizen
- Omdat de toestand van mijn naaste achteruitgaat
- Omdat mijn naaste weinig of geen Nederlands spreekt
- Anders, namelijk

7. Bent u eerste contactpersoon van uw naaste?

- Ja
- Nee

8. Is er weleens iemand anders blijven slapen tijdens deze ziekenhuisopname?

- Ja, namelijk..... (relatie benoemen)
- Nee
- Er verblijven afwisselend andere naasten

9. Heeft u verplichtingen die in uw dagelijks leven tijd kosten?

(meerdere antwoorden mogelijk)

- Werk
 - Zo ja: hoeveel uur per week werkt u ongeveer?
- Vrijwilligerswerk
 - Zo ja, hoeveel uur per week doet u dit ongeveer?
- Mantelzorg of oppassen
 - Zo ja, hoeveel uur per week doet u dit ongeveer?
 - Zo ja, bij wie past u deze verplichting toe?
- Zorgvoorkinderen
- Nee

10. Hoe lang doet u er gemiddeld over om van huis naar het ziekenhuis te komen?

11. Wie heeft u verteld dat rooming-in mogelijk is?

- Mijn naaste
- De verpleegkundige heeft het verteld
- De verpleegkundige heeft het verteld nadat ik erom heb gevraagd
- De arts

12. Wanneer werd u verteld dat rooming-in mogelijk is?

- Op het moment dat mijn naaste werd opgenomen op de afdeling
- Op het moment dat de situatie van mijn naaste wijzigde

- Ik ben er zelf over begonnen
- Anders, namelijk.....

13. Welke afspraken hebben artsen en verpleegkundigen met u gemaakt over rooming-in?

(meerdere antwoorden mogelijk)

- Over tijdstip in- en uitschuiven en opmaken van het bedmeubel
- Over drink- en maaltijdvoorziening
- Over bezoek van andere naasten
- Over bijwonen van de artsensite
- Over deelnemen of overnemen van de verzorging
- Anders, namelijk.....
- Er zijn geen afspraken gemaakt

14. Heeft u zaken moeten regelen zodat rooming-in mogelijk is voor u?

- Ja
(aanvinken wat van toepassing is)
 - Opvangvoorkinderen
 - Opvangvoorhuisdieren
 - Verlof van werk
 - Anders, namelijk
- Nee

15. Door rooming-in:

(meerdere antwoorden mogelijk)

- Kan ik iets voor mijn naaste betekenen
- Kan ik mijn naaste beter ondersteunen
- Voelt mijn naaste zich veilig
- Ben ik gerustgesteld
- Anders, namelijk.....

16. Ik vind het fijn dat ik de mogelijkheid heb om de gehele dag bij mijn naaste aanwezig te zijn

- Helemaal mee eens
- Mee eens
- Niet mee eens, niet mee oneens
- Mee oneens
- Helemaal mee oneens

17. Ik vind het vervelend om weg te zijn van huis

- Nooit
- Soms
- Vaak
- Altijd

18. Door rooming-in heb ik het emotioneel zwaar

- Nooit
- Soms
- Vaak
- Altijd

19. In welke mate wordt u betrokken bij de verzorging van uw naaste? *(bijvoorbeeld helpen bij wassen/aankleden/naar de wc gaan; helpen bij eten, bewegen, innemen van medicijnen, activiteiten ondernemen)*

- Nooit
- Soms
- Vaak
- Altijd

20. Als de verpleegkundige uw naaste komt verzorgen *(bijvoorbeeld helpen bij wassen/aankleden/naar de wc gaan; helpen bij eten, bewegen, innemen van medicijnen, activiteiten ondernemen)*, dan:

- Ga ik meestal van de kamer af
- Blijf ik meestal op de kamer en laat ik de verpleegkundige het werk doen
- Blijf ik meestal op de kamer en help ik de verpleegkundige
- Blijf ik meestal op de kamer en doe de verzorging zonder hulp van de verpleegkundige

21. Indien u taken overneemt van de verpleegkundige, welke zijn dit dan?
(meerdere antwoorden mogelijk)

- Hulp bij wassen en aankleden
- Hulp bij naar de wc gaan
- Hulp bij het eten en drinken
- Hulp bij uit bed komen, lopen etc.
- Hulp bij innemen medicatie
- Hulp anders, te weten.....
- Niet van toepassing

22. Ik vind het fijn om samen met de verpleegkundige mijn naaste te verzorgen

- Ja

- Nee
- Niet van toepassing

23. Door rooming-in heb ik het lichamelijk zwaar (*bijvoorbeeld pijnklachten en vermoeidheid*)

- Ja
- Nee

24. De verpleegkundigen zorgen ervoor dat ik even van de kamer af kan gaan om rust te nemen

- Nooit
- Soms
- Vaak
- Altijd

25. Ik ga regelmatig een luchtje scheppen binnen en/of buiten het ziekenhuis

- Nooit
- 1-2 keer per dag
- 3-4 keer per dag
- Vaker dan 4 keer per dag

26. Ik heb het gevoel dat ik door rooming-in weinig tijd over heb voor mezelf

- Nooit
- Soms
- Vaak
- Altijd

27. Maakt u extra kosten door rooming-in?

- Ja, ik maak extra kosten:
(aanvinken wat van toepassing is)
 - Maaltijden
 - Parkeerkosten
 - Reiskosten
 - Anders, namelijk.....
- Nee
- Ik bespaar kosten

28. Als ik bij mijn naaste in het ziekenhuis slaap, dan slaap ik:

- Beter dan thuis, omdat.....
- Slechter dan thuis, omdat.....

- Even goed of slecht als thuis

29. Wat voor rapportcijfer geeft u uw slaap de afgelopen nacht? *Erg slechtgeslapen* (0)
_____ *uitstekend geslapen* (10)

30. De artsen en verpleegkundigen houden mij actief op de hoogte over de situatie van mijn naaste

- Nooit
- Soms
- Vaak
- Altijd
- Niet van toepassing omdat ik niet de eerste/tweede contactpersoon ben

31. De verpleegkundigen hebben aandacht voor mij

- Nooit
- Soms
- Vaak
- Altijd

32. Denkt u dat verpleegkundigen anders werken als u op de kamer aanwezig bent?

- Ja, want
- Nee, want
- Weet ik niet

33. Ik ben aanwezig tijdens de doktersvisite

- Nooit
- Soms
- Vaak
- Altijd
- Niet van toepassing omdat ik niet de eerste/tweede contactpersoon ben

34. Op deze afdeling is het duidelijk wat ik wel en niet mag of kan doen

- Ja
- Nee

35. Door rooming-in heb ik het gevoel dat er goed voor mijn naaste wordt gezorgd, omdat:
(meerdere antwoorden mogelijk)

- Ik aanwezig ben

- Ik informatie kan geven over mijn naaste
- Mijn naaste zich prettiger voelt
- Ik een deel van de verzorging kan overnemen
- Ik er ben om mijn naaste emotionele steun te geven
- Ik mijn naaste kan stimuleren om meer te bewegen
- Mijn naaste door mijn aanwezigheid rustiger en meer ontspannen is
- Anders namelijk,

36. Mijn algemene ervaring met rooming-in zou ik beschrijven als *erg slecht* (0)
_____ *uitstekend* (10)

37. Wat zou u het Erasmus MC willen adviseren om rooming-in te verbeteren?

Bedankt voor uw deelname!