



**UiT** The Arctic University of Norway

Faculty of Health Sciences

**Recall and understanding of discharge information in observation  
ward patients**

*What did the doctor say?*

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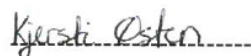


## **Preface**

The idea for this project started with a curiosity of what information the patients are left with and understand after a medical encounter. In the past five years I have been in contact with many patients, and I have got the impression that there is a great variation in understanding of own health condition and medical instructions. I have met patients who have had consultations with their physician, who did not know or understand what the physician actually told them. One female especially made an impression on me. She had returned home from the hospital thinking she had cancer and that she would not get any treatment, when in reality she had a virus. This was a patient who otherwise was well versed and healthy. We who work in health care have a responsibility for that the patients can answer the question; "*What did the doctor say?*", when family and friends ask. Our patient responsibility does not end when the patients leaves the hospital, we also have a responsibility for that the patients can take care of themselves at home. Physicians can give information, but if the patient does not understand it is of no use. Therefore, I wanted to look further into recall and patient satisfaction of discharge information.

I wish to acknowledge my supervisor Eirik Hugaas Ofstad for his guidance in planning, data collection, analysis and editing of this study. Thank you for insightful feedback, reflection and for your time, especially in these special times with Covid-19. I would also want to thank all those who participated in this study – without them, this study would not have been possible.

Bodø, June 2020



Kjersti Østen

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## **Abstract**

### **Background**

Discharge instructions are an important part of patient care and the understanding of these instructions may be critical for self-care in order to avoid readmissions and complications. Previous studies have shown great variations in patient recall and understanding of medical instructions.

### **Objective**

The purpose of this study is to assess the recall of discharge information when information is provided both verbally and written, with especially with focus on information conveyed in the discharge encounter, the patient's recall of instructions, the patient's and the physician's perception of main message and patient's assessment of information and communication.

### **Materials and method**

This is a cross-sectional, interview-based study of patients discharged from an observation ward. Patients were included if they were of age and discharged home, and excluded if insufficient Norwegian language proficiency, mental diagnosis or cognitive deficiency. The discharge encounters were videotaped and immediately after the encounter, the patients and physicians were separately asked a selection of questions. Two weeks after discharge the participants took part in a semi-structured interview via telephone.

### **Results**

Of the 13 patients included, nine patients were discharged with a clear diagnosis, eight had a change in medicine and eleven received information about further plan or advice. The information most patients had deficient recall of was about medication. However, patients reported that they were satisfied with the information and the communication. Patients and physicians emphasized different instructions as the main message in half of the encounters. All the patients received written information, but only half of the physicians reviewed the paper with the patient during the discharge encounter.

### **Conclusion**

Even though high stated understanding and satisfaction of the information among patients, there are potential for improvement. Greater provider awareness of the patient's participation in the encounter and including the patient's perspective may lead to more effective communication. Increased focus on simple communication strategies may be useful.

## **Introduction**

### **Patient-physician communication**

Communication is a fundamental part of our health care. It is the core clinical skill in medicine, and it includes among others information gathering and sharing, decision-making, relationship-building and teamwork (1-3). *“Extensive research has shown that no matter how knowledgeable a clinician might be, if he or she is not able to open good communication with the patient, he or she may be of no help”*(4). The quality of the communication can affect the patients’ health. When done well, both in patient-physician encounters and within health care teams, communication can improve the patients’ health (1, 4, 5). The manner of how the information is communicated is as important as the content of the information (4). Patients are more likely to understand and comply with their medical problems and medical advice, when they trust and understand their physician (4, 5).

### **Discharge information**

Discharge instructions are a critical part of patient care. There are several studies that discuss different aspects of discharge information. A research group in Basel have carried out several studies, where they have focused on content, structuring and use of time (6-9). They concluded that the amount of information should be limited, and the information should be structured. Structured information improves recall, especially among patients with low level of medical knowledge. The same group of researchers also found that physicians often overestimate the patient’s capacity to recall. Furthermore, it has been shown that there is a negative correlation between the amount of information and recall, and a positive correlation between health literacy and recall (10, 11). Some suggest that the patient only need to have knowledge about a few important elements of discharge information, for instance diagnosis, danger-signs, medication and treatment-plan (12).

Patients are daily discharged from hospitals. Effective transitions of care from hospital to home should be safe and timely (13). The transition of care and responsibility from health professionals to the patient can be difficult and vulnerable. Failure in this process, as insufficient discharge information or misunderstanding, can lead to deterioration of health condition and unnecessary readmissions (14-16). One requirement, for the transition to be as smooth as possible, is effective communication.

The Norwegian Institute of Public Health yearly perform user surveys of patients’ experiences of the Norwegian health care. The three latest national reports of inpatient experiences with Norwegian hospitals found that approximately 70% of those surveyed felt that they had

received necessary information about diagnosis and test-results (17-19). About 30% expressed that they had received little or no information to prepare them for the time after discharge. The survey from 2013 found that 10% had low or no understanding of responsibility for own health, and 14 % had some or limited understanding of their own medication (18). More than 80% of patients felt that physicians expressed themselves understandable to a great extent.

### **Recall**

Objective indicators of effective patient-physician communication are recall and adherence. Recall may be affected by misunderstanding of the information given. A study found that less than half of hospitalized patients remembered their diagnosis and treatment plan at discharge (20). Other studies found a range of 40-80% of correct recall (11, 21-23). One of these studies assessed the understanding of discharge information at the emergency department (ED), and they found that 4 of 5 patients had incomplete understanding of the information given (23). In addition, most patients with recall deficits are not aware of it, and some studies found that almost half of the information remembered by patients was incorrect (10, 23). However, in none of the above-mentioned studies, were the patients provided with both written and verbal information. Research has shown that receiving both written and verbal information increases recall, compared to only receiving verbal information (24-26).

### **Health literacy**

Health literacy, as defined by the Institute of Medicine, is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (27). In other words; Does the patient have a basic health knowledge to understand health care information? Some studies have shown that higher levels of health literacy improve recall of medical instructions (7, 11).

Patients with low health literacy have more contact with the health care system, more misunderstandings of medical instructions and higher rates of medical errors (28). When patients do not understand or do not remember their instructions, managing their health problem is difficult.



## **Aim and objective**

The purpose of this study is to assess the recall of discharge information when information is provided both orally and written, more precisely divided into six research questions:

- What information do the physician convey to patients during discharge encounters?
- How does the patient's prior knowledge and the physician's and patient's behaviour in the discharge encounter affect the dialogue?
- When asked directly after the discharge encounter, what is the main message of the discharge information according to the patient and the physician?
- When asked two weeks after discharge, what does the patient remember of discharge information?
- When asked two weeks after discharge, how do patients assess the information they received at the hospital, in terms of quality, quantity and their own understanding of information provided?
- Overall during the process, how does written versus oral information affect the quality of information given during the discharge encounter, affect what patients and physicians weight as important directly after discharge, and affect patient recall and understanding two weeks after discharge?

## **Method**

### **Study design**

This is a cross-sectional, interview-based study of 13 patients discharged from an observation ward.

### **Setting**

Nordlandssykehuset (NLSH) is a part of the Northern Norway Regional Health Authority, and covers the secondary care of Salten, Lofoten and Vesterålen. The largest somatic hospital is in Bodø.

The study was conducted at the observation ward at NLSH Bodø. The observation ward allows patients to be observed on a short-term basis, while they are assessed for further admission in the hospital or discharge within 24 hours (29). The purpose is effective medical examination and treatment. More than half of the patients are discharged within 24 hours. However, a large portion of patients receive an extensive outpatient follow-up after discharge. Common conditions treated in the observation ward are chest pain, atrial fibrillation, syncope, intoxication with alcohol and/or drugs, abdominal pain and uncomplicated infections (such as urinary tract-, lower respiratory- and skin infections).

The Emergency Department of NLSH Bodø cared for approximately 2200 patients during a period of 15 weeks in 2018 (30). 869 patients were admitted to the hospital, of which 34% was admitted to the observation ward. Of those patients not admitted to the hospital, 73% was discharged home.

At NLSH, all discharged patients receives a 1 or 2 page written discharge summary (*epikrise ved utreise - EVU* in Norwegian). The key components that should be included in a discharge summary are: 1) the main diagnosis, 2) the relevant history, 3) the examination and results, 4) the medical judgement including treatment/medication information and 5) follow up information and aftercare instructions (31, 32).

### **Selection of participants**

The data was collected from patients discharged home from the observation ward. The goal was to have a patient volume of 20-30 patients.

Inclusion criteria were age above 18 years and discharged home. Patients were excluded if they did not speak or write Norwegian, had a mental diagnosis or cognitive deficit, were

influenced by alcohol or other drugs at discharge. Patients were also excluded if they had been readmitted in the period from discharge until the interview.

### **Recruitment of participants**

Potential participants were approached by student Kjersti Østen, prior to discharge, usually the day after admission. They received oral and written information about the study, and when the patient so decided, written consent was obtained. The patient information letter explained the broad aims of the study: to explore what patients remember and understand of the information given at discharge. In the information letter the study was given a more people-oriented title “What did the doctor say?” (appendix 1 and 2). The recruitment process took place during two weeks in August and one week in October 2019.

Information about the study was sent out to all personnel at the ED and observation ward. Physicians who consented to participate in video-recorded encounters, received the same information, orally and written before asked to consent.

### **Procedure and data collection**

Demographic data such as age and sex were collected, and health literacy was assessed. The discharge encounters were videotaped in a suitable room. Immediately after the encounter, the patient and physician were separately asked a selection of questions (see appendix 3 and 4). Two weeks after discharge the participants took part in a semi-structured interview via telephone, conducted by the student. The interviews were recorded on tape. Both the videotapes and the interviews were transcribed verbatim. Information obtained from videotapes and the interviews was analysed using a qualitative method described in the section *Data collection* below. Collected data were stored on a secure encrypted USB flash drive designed to hold confident and sensitive information.

### **Literature search**

The search on the PubMed and MEDLINE databases were executed with the following keywords/MeSH-terms: ‘patient discharge’, ‘plan’, ‘summary’, ‘mental recall’, ‘patient’, ‘communication’, ‘comprehension’ and ‘emergency medical services’, in various combinations. Example shown in figure 1. Also, references from selected articles were checked for relevant articles.

**Figure 1.** Example of literature search in PubMed

History		<a href="#">Download history</a> <a href="#">Clear history</a>		
Search	Add to builder	Query	Items found	Time
#7	<a href="#">Add</a>	Search ("Mental Recall"[Mesh]) AND "Patient Discharge"[Mesh]	43	04:08:40

## Questionnaire development

Health literacy was assessed by using a three-question subjective questionnaire (33, 34), where the patients were to self-report their own difficulty with understanding information or perform reading tasks in health care encounters (appendix 4). The questionnaire was translated into Norwegian. To each question the participants scored themselves on a 5-point scale. Thereby, giving a total score of minimum 3 points and maximum 15. A score of 9 or lower indicated low/inadequate health literacy.

An interview-guide was developed to form the basis of the semi-structured interview (appendix 5). The interview started with open-ended/prompted questions for free recall, with additional, more targeted, questions if the topic had not already been covered by the interview. The additional questions were to help the patient with cues without helping the patient remember. All the questions were not asked to all the patients. The interview-guide underwent minor modifications and improvements after the first few interviews.

## Data analysis

Systematic text condensation (STC) is a method, developed by Kirsti Malterud, for analysis of qualitative data. The aim of this method, as with other qualitative methods, is to gain knowledge about human experiences, values, interactions and behaviours.

STC is based on a four-step procedure (35, 36).

- 1) Total impression.

Get to know the material by reading all the texts using a top view. Summarize the information and assess possible preliminary themes.

- 2) Identifying and sorting meaning units

The purpose is to organize pieces of material to study closer. A detailed systematic review of the text is used to find the meaning units. Malterud describes a meaning unit as *“a text fragment containing some information about the research question”*. Then the meaning units are sorted to potentially themes, which may be adjusted later, a process called coding.

- 3) Condensation

The coded meaning units are condensed together. All the pieces of material in each group are placed into subgroups, called an analysis unit or condensate. A condensate is an artificial quotation where different quotes are fused together to one quote, the original terminology used by the participants.

#### 4) Synthesizing

Recontextualization – do the results we have read from the processed material correspond to the original text?

Initially, the plan was to apply STC on the data in this study. However, when going through the data material with the four-step procedure it became clear that this method was not the proper method to analyse the data. Instead, only the first two steps were used. More details about this in the discussion.

Communication performance of each patient-physician encounter was assessed with some attention to use of communication techniques, overall impression, non-verbal communication such as body language, voice (level and speed), words used (medical and non-medical terms), confidence and clarity of physician, in addition to physician’s engagement and behaviour.

### **Ethics and approval**

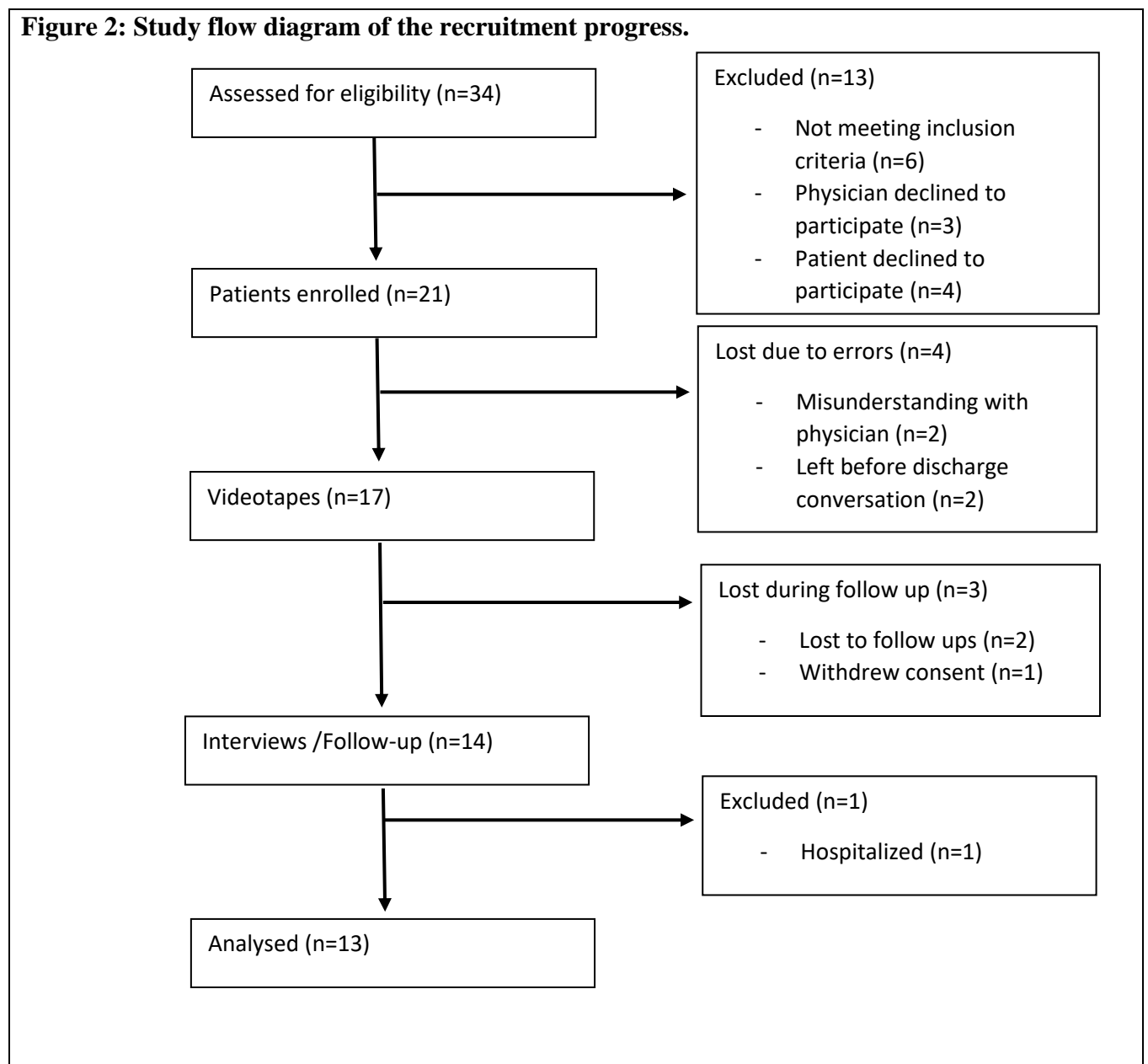
The study recorded data on individual patients. Therefore, approval was obtained from the Norwegian Social Science Data Services (NSD) and from the privacy ombudsman at NLSH. NSD considered that the processing of personal data in this project is in accordance with the privacy regulations. An orientation was submitted to the Regional Committee for Medical and Health Research Ethics (REK). REK concluded that the project did not require a formal ethical evaluation process.

### **Time schedule**

<b>Table 1: Overview of time period and work tasks</b>	
January-October 2018	Find an academic supervisor and choose a thesis. Formulate a thesis statement and write a project plan.
January 2019	Participate at OCHER (Oslo Communication in Healthcare Education and Research)
January-July 2019	Apply to NSD and REK. Develop an interview-guide, information sheets and consent forms
August 2019; two weeks before practice period	Data collection at the observation ward NLSH
August 2019-Mars 2020 (practical period)	Read literature. GRADE articles. Write introduction and method. Start analysing data.
Mars-June 2020	Analysis of data. Complete writing the master’s thesis

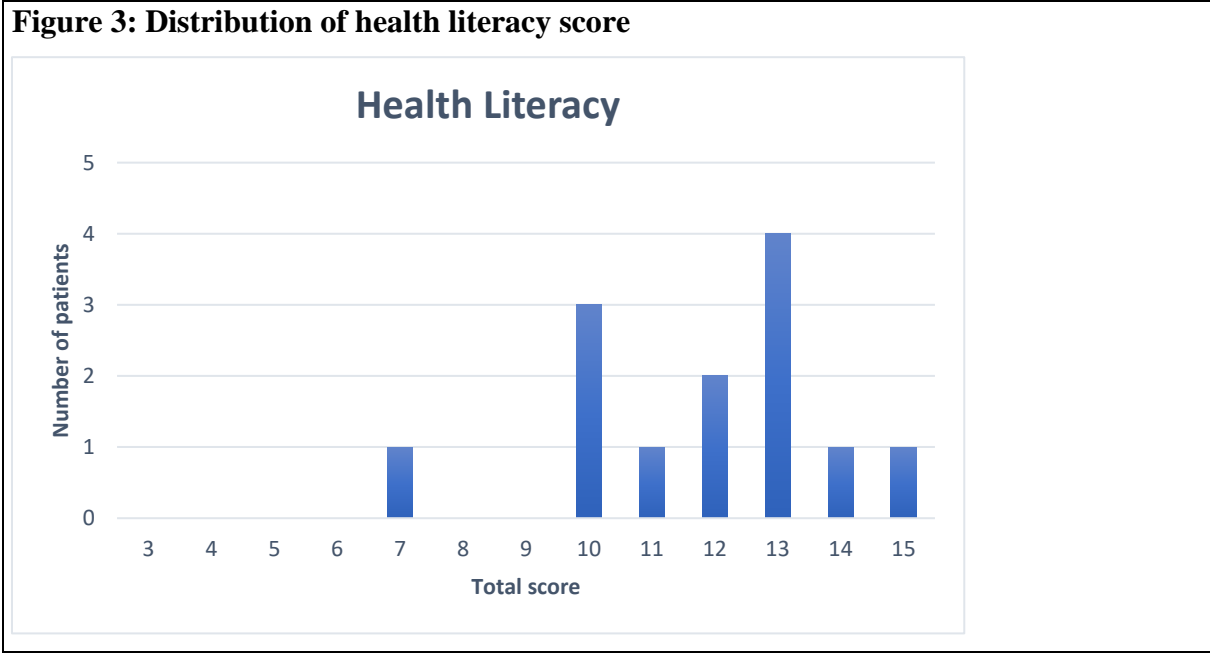
## Results

During the study period, in total 34 patients were assessed for eligibility. Six patients did not meet inclusion criteria and three physicians declined, thus 25 patients were approached. 21 patients agreed to participate. Of the 21 who agreed to participate, 17 had their discharge conversation videotaped. 13 patients completed the phone-interview, and were enrolled in the analysis. More details are shown in figure 2.



Demographic data and health literacy for the sample is provided in table 2. Distribution of subjective health literacy is shown in figure 3. One patient had a score of  $\leq 9$ , indicating low/inadequate health literacy. The rest had a score corresponding to adequate health literacy.

<b>Table 2: Patient characteristics/Demographic data</b>		
Sample (n=13)		
<b>Sex</b>		
Female	8	(61,5%)
Male	5	(38,5%)
<b>Age</b>		
Average age	64	[43-81]
Age $\leq 50$ yrs	3	(23,1%)
Age $> 50$ yrs	10	(76,9%)
<b>Health literacy</b>		
Inadequate	1	(7,7%)
Adequate	12	(92,3%)



**Information flow in discharge encounters and recall**

Patients received a mean of 7,2 items of information each, ranging from 3 to 16 (see table 3). In the analysis, information was placed into one of three categories; diagnosis/cause, medication and further plan/advice.

Diagnosis

Four of the 13 patients were discharged without finding the cause of their symptoms. They were admitted for hypertension, dyspnoea, chest pain/dyspnoea/palpitation and dizziness, respectively. All of them were examined and the most serious causes of their symptoms were

excluded. At discharge, they were all asymptomatic and in good condition, and had a plan for further examination either with their general physician (GP) or at the hospital.

Eight of the nine patients who got a diagnosis recalled it when asked two weeks after discharge. One of these had partial recall, where the patient remembered that there had been an infection, but not the name of the infection. Examples of classification of recall (no, partial, complete) are shown in table 4.

<b>Table 3: Information and recall</b>	
	Sample (n=13)
Mean items of information	7,2 [3-16]
Known cause	9 (69,2%)
Recall of cause	
- Complete	- 7/9
- Partly	- 1/9
- No	- 1/9
Change or new medicine	8 (61,5%)
Recall of medication	
- Complete	- 4/8
- Partly	- 3/8
- No	- 1/8
Information about further plan or advice	11 (84,6%)
Recall of advice	
- Complete	- 6/11
- Partly	- 4/11
- No	- 1/11

### Medication

Eight patients had a change in medication or got prescribed a new medicine during their stay at the hospital. Four had complete recall of their medicines, three had partial recall and one had no recall. The group with complete recall all had only one change in medication. Of those with partial recall, two had one change and one had three changes. One patient did not remember any of the instructions about medicines. This patient had two changes in medicines.

### Further plan and advice

11 patients received information about further plan or advice to follow at home. Of them, six had complete recall at two weeks. Four partially remembered the information and one did not remember any of the instructions. The latter received the most instructions.



<b>Examples</b>	<b>Information provided in videotape encounter</b>	<b>Patient interview</b>	<b>Omitted or discordant information</b>	<b>Rating given</b>
Diagnosis/conclusion	Erysipelas	Skin infection	Did not remember the name	Partial recall
Treatment	If symptoms of new episode of atrial fibrillation take a tablet of Tambocor, if no change in 1 hour, take one more.	In case of atrial fibrillation take 1 tablet immediately, thereafter 1 more after 1 hour if no change	Did not remember name of medication	Partial recall
Further plan/advice	Contact GP if dizziness, chest pain or new episode of atrial fibrillation Echocardiography in 5 months. Check of pacemaker in a year	None	No recall of further plan or advice	No recall

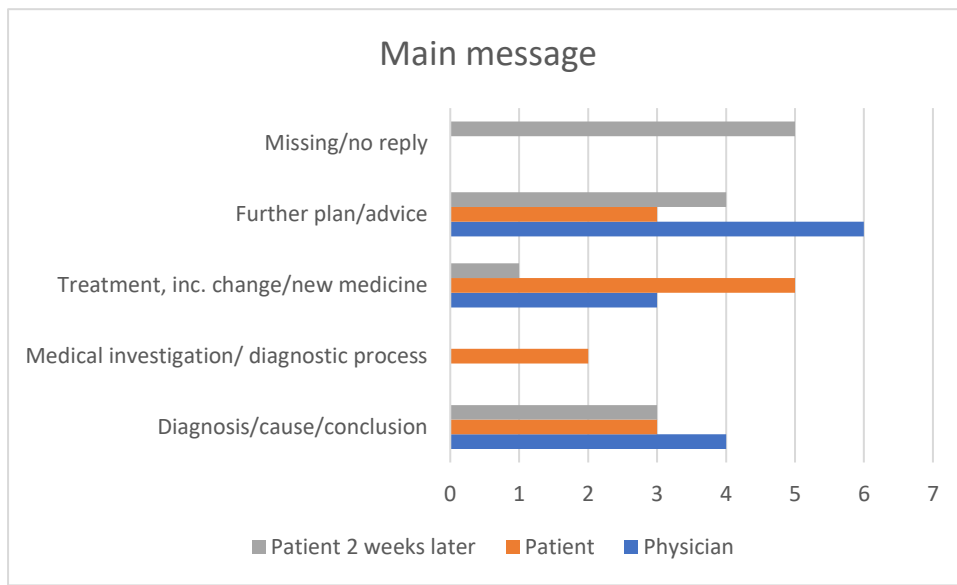
### **Main message**

Directly after the discharge conversation, both the physician and the patient were asked what they felt was the main message in the conversation. The answers were placed into five categories: diagnosis/conclusion, medical investigation, treatment including change in existing medicine or prescription of new medicine, further plan/advice or missing/no reply. A distribution of the replies in the five categories are displayed in figure 4. Figure 5 shows the results for each individual encounter, and the concordance between what the patients and physicians replied. Each category is illustrated in its own colour, concordance is illustrated by a green arrow, while non-concordant replies are illustrated by a black line.

About half of the physicians stated that they thought that information about further plan and advice was the most important information that they provided. Four said that the conclusion of the findings/diagnosis was the most important. The rest gave information about treatment/medicines as the main message.

Five patients stated that information about treatment was the most important information, three diagnosis/conclusion, three further plan/advice and two medical investigation.

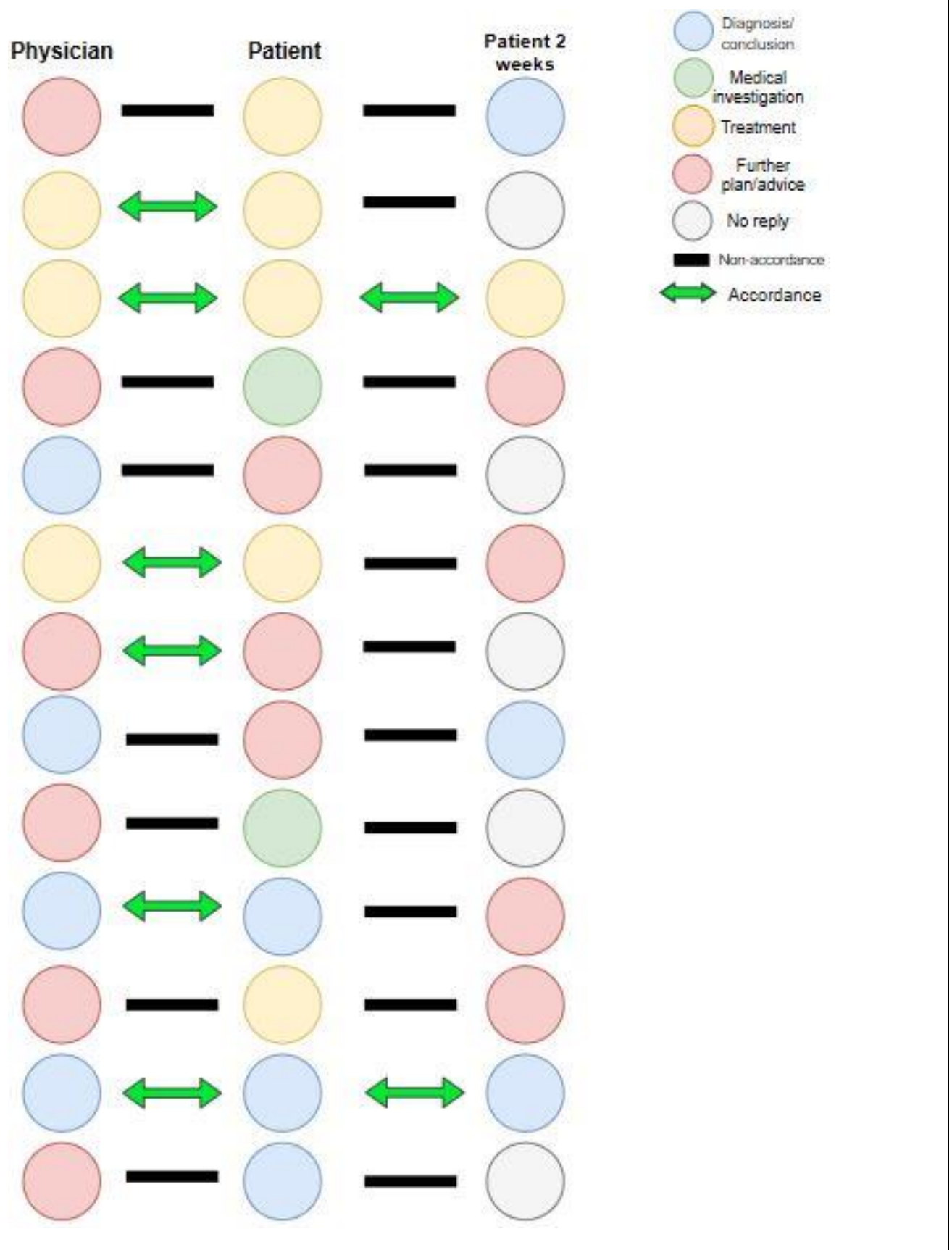
**Figure 4: Main message divided in categories**



Patients were asked the same question at the two-week interview. Eight patients replied, of which four stated further plan/advice, three diagnosis/conclusion and one treatment as what they thought was the main message from the discharge information. Only two patients gave consistent replies at discharge and at the two-week follow up.

As shown in figure 4 there are some concordance between what the physician and patient perceive as the main message. The replies concur in six of thirteen encounters.

Figure 5: Relation between physicians' and patients' thoughts of main message



### Assessment of the information

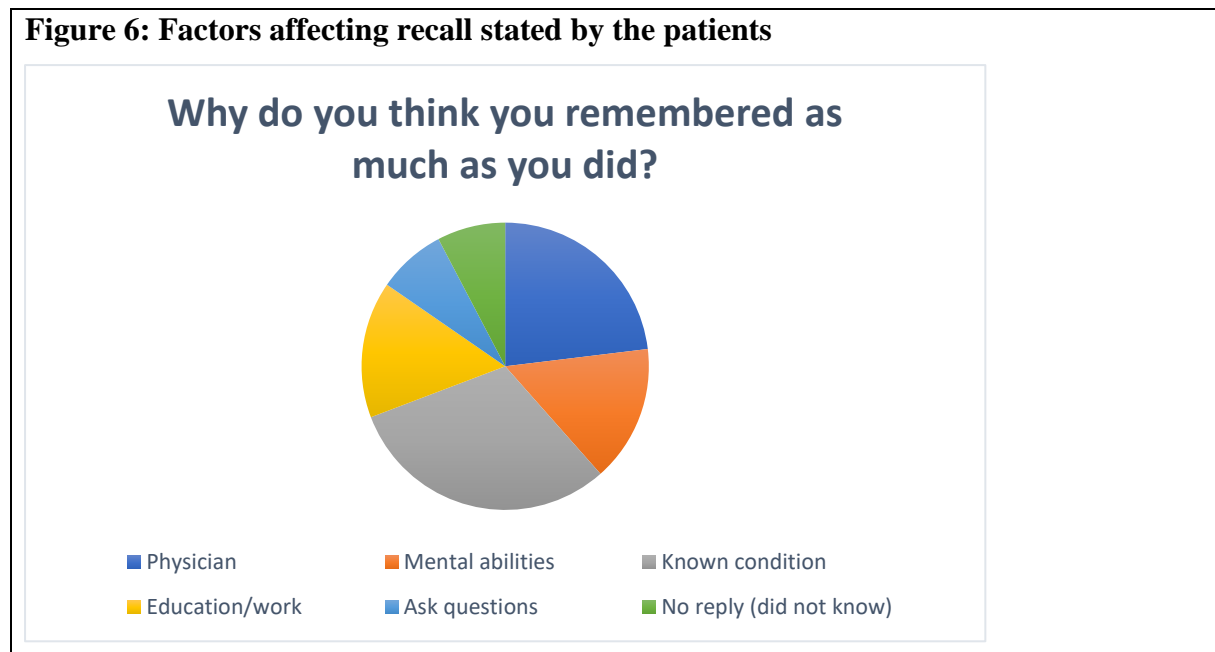
All patients were asked at the two-week follow up what they thought about the information provided to them. All except two assessed the information as comprehensible and had not felt uncertain about the information during the two weeks after discharge. Two patients had felt insecure about their medication, specifically if they should continue taking the medication or not. One of them had been in contact with a physician at the hospital after discharge to clarify the instructions.

None stated that they wanted more information from the physician. Three patients had searched for more information themselves, and two patients had partners who had searched for more information for them.

### Factors affecting recall

When asked what they thought affected their recall (“*Why do you think you remembered as much as you did*”) 12 of 13 patients replied. Results are illustrated in figure 6.

**Figure 6: Factors affecting recall stated by the patients**



Four patients had a known condition. They had been admitted before (up to three times) and received information about the condition then. Two patients worked in the health sector and thought this improved their recall, and three answered that they had a good physician. When asked to elaborate three main factors were brought up; good communication with the physician, safe atmosphere, and a calm and clear physician. One patient explained her experience of a good physician like in the following quote;

*“I think I got good communication with the doctor. It was a two-way communication. As mentioned, the doctor asked if there was anything I wanted to ask about. If there was something I did not understand, I just had to say so”.*

Two gave mental abilities as a factor, where one felt she was a well-versed person and one said he had a good memory, especially related to health. One patient said she remembered because she asked a lot of questions.

*“I asked a lot. I asked repeatedly. And I also said that I did not completely understand. I expressed that I did not understand why they were so focused on stroke and the brain when the problem was my stomach (...) But after thinking about it, I understood why”.*

### **Behaviour and nonverbal communication**

Overall, all physicians expressed interest in the patient, and were focused on the encounter. The physicians were faced to the patient. All of them had good eye contact with the patient, sat calmly and were not fiddling. Two physicians and one patient used their hands actively to gesticulate, explain and illustrate. Body language did not show any signs of hurry or impatience. In all the encounters the physicians expressed confidence; either in body posture, verbally or both. One exception was an encounter where the physician appeared anxious and less confident.

Four physicians changed position during the encounter, from sitting face-to-face with the patient to leaning forward to the patient or to sitting next to the patient. In all cases, the change in position was in connection with review of the written information.

### **Atmosphere and use of language**

There was a general relaxed atmosphere in all the encounters. Most of the encounters were in a semi-formal setting, with no clear hierarchy between physician and patient. The physician usually led the conversation, there was an openness for questions and thoughts.

In general, there were used appropriate volume and pace in voice. One physician talked in a high pace. Two patients had reduced hearing, in both cases the physician spoke with a louder voice and sat closer to the patients than normally. No signs of misunderstanding or insecurity because of language or unclear enunciation were observed.

When medical terms were used, an explanation usually followed. For example;

*“It’s significant for orthostatic hypotension. That means that when you stand up the blood pressure drops”.*

### **Structure in the discharge encounter**

In about half of the encounters there were an apparent plan of structure from the beginning of the encounter. One physician introduced in this way: *“I thought we could talk about what has happened and why we have done what we have”*. Three encounters started by going through the EVU and three others started mapping what the patient already knew about what had happened and their thoughts about it. One physician seemed to have a plan/checklist for the encounter, and using it structured saying *“Point one...Point two...”* as new items of information was presented.

Checkpoints during the encounter was used by one physician. After each item of information given, the physician asked *“Okey?”* or *“What do you think about that?”* to confirm that the patient was following, before moving on to the next item.

In five encounters the physicians summarized the conversation at the end. *“Altogether, we find no signs of heart attack or arrhythmia. There have not been any changes in your medicines. Also, you need to get an appointment at your GP within two weeks”*. None of the patients were asked to summarize themselves. However, one patient made a summary on her own initiative. *“Okey, so there were several concurrent factors causing my syncope. It’s not dangerous and I can live my life as normal”*.

### **Use of written information in the encounter**

In 11 of the 13 encounters written information (the EVU) was brought to the discharge conversation, and it was used actively (as a part of the conversation) in eight of them. Six physicians went through the EVU with the patient; three went through parts of the EVU (for example the medicines) and three did a complete review. Two physicians asked the patient to read the paper by themselves during the encounter.

All the patients except one, received an EVU before they left the hospital. The exception was a patient who was asked if he wanted the EVU before discharge or sent by post later, where he chose the latter.

Using the EVU in the discharge encounter gave an impression of a more organized communication, and it seemed easier for the patient to be attentive and participate more.

### **Questions**

In 12 of 13 encounters the patients were asked directly if they had any questions or if something was unclear. Two patients were asked twice. The question was brought up usually

at the end of the conversation (10 of 13 events). During the encounter five patients asked questions, where one to seven questions were asked. Most questions (10 of 16) were about further plan/advice. There were three questions about cause and two about medication.

### **Shared decision making**

In most of the encounters a further plan was already made by the physician before the discharge encounter. Exceptions were three encounters, of which two patients were partly involved and one patient who got the full responsibility of making the decision. In one encounter, the physician let the decision of whether to start with a new medication or not, be taken by the patient. The physician gave information about background for starting the medication and risks related to it.

*“After an episode of atrial fibrillation there is a risk of formation of clots in the atriums. The risk is based on several factors as high blood pressure, heart failure, diabetes and heart-disease. You do not have any of these risk factors, so your risk score is 0. Therefore, I would like to ask you if you want to take blood-thinners for four weeks or not. There are no right or wrong. Because of your low risk, there is no absolute recommendations to start the medication, but if you had had high blood pressure or any other risk factors it would be recommended. It’s your choice. I do not want to put a pressure on you to take any medication, I just want to inform you about the rationale of why we do it. Some doctors would have given you blood-thinners just to be on the safe side. However, a study of 90 000 patients showed that those with the lowest risk had a clotting-risk of less than one percent. Therefore, I want to know what you think about this”.*

There were two similar encounters with corresponding problems and decision to be made. In both of these encounters the physician provided information about risks. However, the information was used to state the reasons for the physician’s decision, instead of being used to make a shared decision. The patients were not asked about their thoughts.

*“For the present, your risk score for clots is low. That is what we think about when you have these episodes of atrial fibrillation. At some point when you have more risk factors and are older, we have to decide if it’s time to start blood thinners. At this point your risk is very low. We have to weigh the risks of bleeding to the risk of clotting. I do not think you should have blood thinners”.*

## **Discussion**

This study showed that despite the patients high stated levels of satisfaction with communication, many patients did not demonstrate full recall of discharge instructions. The information most patients had problems remembering was instructions about medication and other treatment. These findings are in accordance with several other studies (11, 23, 37), of which Engel et al. found that one in three patients had problems comprehending instructions about treatment. Possible explanations of this may include level of health literacy, physical and mental situation/state, and amount of information received.

Regarding the amount of information provided, there were considerable differences between the encounters in this study. The mean items of information in this study was about seven. Compared to previous studies of recall (7, 8, 38, 39) where patients received 28-56 items of information, the patients in our study were given significant fewer items. This may be due to the setting at an observational ward, the extent of medical investigation, the patient's prior knowledge of own condition or time (made) available for the discharge conversation. Hence, as our patients received fewer information items one could expect recall should increase.

Even though our findings of recall are comparable with findings in previous studies, these studies show a huge variation in recall. A systematic review of 51 articles found a variation of 8-94% in recall of verbal information and 23-92% of written information (25). The studies also have a variation in assessing recall regarding time of recall (immediately, short term, long term), amount of information items, type of information, etc. Based on these differences, it is important to consider these factors before comparing recall. Another aspect to have in mind, is the possibility that patients with deficient recall had followed the instructions but recalled it incorrectly in retrospect.

Patients may have a false impression of comprehension when they believe they understand more than they actually do. Engel et al. showed that patients with deficient comprehension of discharge information often fail to perceive them (23). In other words, the patients are not always aware of what they do not understand, which may give them a false sense of having enough and not needing more information. As recall of discharge instructions is a prerequisite for patient compliance, this may result in non-adherence to medical instructions, that later might lead to delayed recovery or complications.

Another finding in this study, was that physicians and patients often do share the same opinion about main message. The discordance between patient's and physician's assessment



of most important information may be due to inadequate communication and little focus on patient's perspective. The literature on patient participation in discharge encounters is scarce, but one study found a positive relationship between patient participation and patients' recall (40). If the patient is not encouraged to share their point of view, the physician may only focus on the information he/she believes is the most relevant. Patient participation may help the physician to understand the patient's goals, concerns and needs for information, and thereby build a more effective communication. Also, when patients receive information they assess as relevant, recall and compliance might increase. However, the challenge can be finding ways to make patients actively participate in the discharge encounter.

### **Strategies to make the patients actively participate in discharge encounters**

One effective way to increase patient participation is asking for their opinion, ideas and goals. Even though some patients may not be used to or feel comfortable with having/sharing their opinion and participate in medical decisions, it is important that the physicians arrange for this to be possible. By showing a willingness and openness for the patient to have an active role in the encounter, the patient may feel that there is room for them to participate. A starting point of the encounter can be mapping the patient's ideas, concerns and what information they want to receive. In this way the information can be more patient-oriented, and the patients can receive tailor-made information that is more relevant to them. Also, it may enhance the patient's role in creating plans including treatment, and for decision making. The term shared decision making (SDM) is used when the patient and/or family, and the physician cooperate to develop successful therapeutic plans (41). Identifying the patient's goals as a starting point of SDM can give a more shared understanding of how to proceed. In addition, focus on patient perspective may reveal different views of explanations and misunderstandings, and thereby creating a golden opportunity to clarify this.

Another effective strategy to make the patient more actively involved, could be using communication confirmation methods in the encounter. Communication confirmation methods such as "teach-back", can be a useful tool for the physician to confirm and ensure that the patient understand the information provided to them. The "teach-back" method lets the patients repeat the information. The patient may be asked to tell a specific part of the information or to summarize all the information. For example, make the patients repeat how they are to take their medication and for how long. A summary can provide structure to the encounter, in addition to giving a survey of the most important information. In addition, repeating the main message can clarify and prevent the message from drowning in the all the

other information. In this study none of the physicians requested the patients to summarize or restate the instructions. Thereby they missed an opportunity to increase patient participation and to uncover misunderstandings.

Written and verbal information in discharge encounter can have an effect on both patient participation and recall. Several studies, including a systematic review of recall and manners of providing discharge information, concluded that using written information in addition to verbal recall improves recall of instructions (24, 25). One advantage using written information is that the patient has a piece of paper to review at home. Using written information in the discharge encounter is also a useful way to show the patient where they can find information and at the same time explain it to ensure clarity and uncover difficulties. In addition, it serves as a communication tool and provides structure to the discharge encounter. It may be easier for the patient to be attentive and have a more active participation when they can see the written information as well. When examining the videotapes in our study, those encounters actively using the written paper seemed easier to follow as it gave more structure. However, recall and patient assessment of the encounters did not seem to be affected by degree of structure, or the use of written information in addition to verbal. Research on use of structured information and recall have shown inconsistent results. A randomized trial including students showed that structured information increased recall, with most benefit for those with low health literacy (7). Information was given in an organized manner using a book metaphor by first giving a survey using table of contents and chapter headings before giving details. Other studies have shown that structuring information do not increase recall (38, 39).

Patients and physicians do not always share the same perspective. As shown in figure 4 the physicians and patients only had the same perception of the main message in about half the encounters. There is limited research on the relation between patient's and physician's perspective. A study from Germany examined if patients and physicians had the same or different perception of the patient's preferences. Both patients and physicians were asked to rank 17 therapy characteristics for their importance, for instance effectiveness and physical quality of life (42). The results showed that their perceptions were very close. Discharge encounters should address the patients need for information, and it is therefore important to share or be aware of each other's perspectives. Further research is needed on the relationship and awareness of patient and physician's perspective.

## **Strengths and weaknesses**

Using videotapes of the discharge encounters and interviews at the two weeks follow up gave a great amount of information. The use of questionnaire at the follow up would probably not have given as much information as follow-up questions would not have been possible.

Because of the limited time to collect data, we decided on two weeks to follow up. Even though the final sample size was a bit smaller than expected, it was still large enough to get a rich database to shed lights on the study's objectives. The objectives of this project were chosen because of its clinical relevance. Although limited by a small sample size, this study illustrates the importance of good communication. Communication, recall and understanding are important in all aspects of health care with patient-contact.

There are several weaknesses in this study. The health literacy score used was developed in the US and probably taps better into American conditions than Norwegian. Especially the third question ("*How confident are you on filling out forms by yourself?*") may not be so important in Norwegian health care. There are no Norwegian health literacy scores, and the other scores available were very extensive and time-consuming. Therefore, this short health literacy score was chosen. Moreover, the selection of patients may have influenced recall. Patients who were not fluent speakers of Norwegian were excluded from the study. Thus, the sample did not include those who – due to language barrier - may have the greatest difficulty in understanding given instructions. The most distinct weakness of this study is that it only contains data of 13 patients. Seven patients and physicians declined to participate, four patients were lost due to misunderstandings around discharge and three were lost in follow up. Some dropouts are to be expected, however those patients lost because of misunderstandings were unnecessary. Clearer messages and more information about the study may have improved this, which stress the importance of good communication.

## **Improvements**

This study presents a number of limitations. The study setting was an observational ward and the study population was therefore a selection of patients who had a short medical examination and did not require further admission. Several patients were discharged without a diagnosis, but with a plan for further medical investigation. The information they received was mostly exclusion of the most serious conditions and reassurance. Thus, if the patients had been diagnosed, they might have received more specific information about the condition, treatment, advice and follow up. In addition, if data collection had taken place in another department, for example department of cardiology, patients may have had a longer stay with a

more extensive medical investigation and subsequent results. Thereby, receiving more information about diagnosis, results, treatment, and follow-up than in the observation ward. Comparing recall with other studies where they receive a larger amount of information than in this study, may give a false impression of recall. However, doing the study in another department would have required more time because of a lower amount of discharge encounters than in the observation ward.

Also, the setting may be a confounding factor on communication. Having the discharge encounter videotaped and having an observer in the same room, may have influenced the discharge encounter. Participants, both patients and physicians, may modify their behaviour in response to their awareness of being observed, an effect known as the Hawthorne effect or the observer effect. Hence to the physicians; Did they give information differently than they normally would have? Did they use more time to explain? Did they rush to get away from the video camera? Did they feel it was a test of performance? Not all physicians seemed as comfortable having the encounter videotaped, which may have affected the consultation. As for patients; Were they more aware of the information they received because they knew they would be 'tested' later? Did they ask fewer questions because they were observed?

During the data collection we gained knowledge that made us adjust the course and objective. Experiences from the interviews made us consider and adjust the original plan of a more quantitative view. The original plan was to assess how much the patients remembered and understood of the information. Because of the small sample size and the great difference in how much information the patients received, we chose to change to a more qualitative approach. This may have been avoided if there had been a pilot-testing of the interview guide before using it on the study population, but again time was the limiting factor. Also, we had to adapt the analysis method to our data because of limited material in each coded group, which made condensation difficult. A trained interviewer with more knowledge of interview techniques may have improved the data collection. The interviewer did not have any training or practical experiences with this type of data collection. Also, the interviewer did participate at the discharge encounter which may have influenced the interview by subconsciously giving cues. On reflection, the person responsible for videotaping the discharge encounter and the person responsible for the interview should not be the same person to reduce bias.

## **Conclusion**

This study showed that about half of the patients had problems recalling instructions about medication, further plan and advice, and in half of the encounters the patient and physicians did not share the same perspective on the main message of the encounter. However, the patients themselves considered the information understandable, reported no need for further information and they were satisfied with the communication. Even though all patients received written information, only about half of them reviewed it with the physician. It appeared to be no difference in subjective perception of understanding, assessment of amount of information or quality of the encounter between the patients getting a review and those who did not get a review.

Physicians can communicate information, but if the patients do not understand it, it is of no use. Therefore, physicians must be aware of the importance of effective communication in discharge encounters. The discharge encounter should not be a monologue, but a dialogue, and it's a golden opportunity to explore the patient's perspective and make shared decisions. Greater provider awareness of the patient's participation in the encounter and including the patient's perspective may improve communication. Simple strategies as asking the patient for his thoughts, using "teach back" and summaries, and using written information as a communication tool in addition to verbal information may be useful.

Further research is needed to examine 1) if deficient recall is due to impaired memory of instructions or impaired memory of the executions of the instructions 2) recall in patients with cognitive deficits, mental diagnosis or language barrier and 3) the relationship and awareness of patient's and physician's perspective.

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## GRADE evaluations

The Grading of Recommendations Assessment, Development and Evaluation (GRADE)

<b>Reference:</b> Engel KG, Heisler M, Smith DM, et al. Patient Comprehension of Emergency Department Care and Instructions: Are Patients Aware of When They Do Not Understand? Ann Emerg Med 2009; 53: 454-61.e15.			Study design: <b>Cross-sectional study</b>
			<b>Grade - quality</b> <span style="background-color: #008000; color: white; padding: 2px;">+++</span>
<b>Objective</b>	<b>Material and method</b>	<b>Results</b>	<b>Discussion/comments/checklist</b>
To assess patients' comprehension of their ED care and instructions and their awareness of deficiencies in their comprehension	<b>Recruiting participants</b> Research assistant used ED computer records to identify appropriate patients. Immediately after discharge from the ED, patients were approached by one research assistant.	<b>Main findings</b> 78% had deficient comprehension in at least one domain  Most patients with comprehension deficits failed to perceive them	<b>Checklist:</b> <ul style="list-style-type: none"> <li>• <b>Is the objective clear?</b> Yes</li> <li>• <b>Who was included/excluded?</b> Participants who failed the Mini-Cog test was excluded</li> <li>• <b>Was the groups equal at start?</b> No differences were noted in the demographic data or overall satisfaction scores for the sample and refusal populations</li> <li>• <b>Were the participants accounted for at the end of the study?</b> Yes. 29 participants did not participate in their interviews. 25 were not able to be reached and 4 refused at the telephone contact. 4 participants did not complete their interview. 1 participant failed the Mini-Cog test</li> <li>• <b>Can the results be transferred to practice?</b> Yes, the study population can be representative, at least to other ED patients</li> <li>• <b>Were all the outcomes assessed?</b> Yes</li> <li>• <b>Is there other literature that supports the results?</b> Yes. Similar results have been found in previous studies.</li> </ul> <b>What does the authors discuss as:</b> <b>-strengths:</b> assessing patient awareness of deficits <b>-weakness:</b> the study was conducted at 2 teaching hospitals in Michigan – limiting the generalizability, subjective comprehension scores, concordance-coding, delay in telephone interview, bias in reporting comprehension difficulties <b>Do the results have plausible explanations?</b> Yes. The authors discuss among others that instructions are given at the end of the visit when the patients are anxious to leave and therefor may feel less inclined to ask questions. Also, some instructions may only be written, and not discussed
<b>Conclusion</b>	<b>Inclusion-/exclusion crit.</b> Inclusion: Discharged from the ED Exclusion: Inability to speak English, younger than 18 years, inability to speak or hear, discharge from the ED to another facility or unit, a primary diagnosis of alcohol intoxication or abuse, resident of a prison facility, compromised mental status		
Many patients do not understand their ED care and their discharge instructions. Most patients appear to be unaware of their lack of understanding	<b>Data</b> 366 patients were approached. 175 agreed to participate. 146 were enrolled in the study. 141 completed the interview. The total sample population was 140.		
<b>Country</b>	<b>Outcome -validation</b> Perceived comprehension Perceived difficulty of understanding Recall		
USA	<b>Statistical methods</b> Descriptive statistics Stata 9.0		
<b>Year data collection</b>			
2003-2004			

<b>Reference:</b> Ackermann S, Ghanim L, Heierle A, et al. Information structuring improves recall of emergency discharge information: a randomized clinical trial. Psychol Health Med 2017; 22: 646-62.			Study design: RCT
			Grade - quality
			+++
Objective	Material and method	Results	Discussion/comments/checklist
To examine the extent to which structuring Emergency Department discharge information improves the ability to recall that information, and whether such benefits interact with relevant prior knowledge	<b>Recruiting participants</b> Participants were students from Universities of Basel and Mannheim, and they were recruited during three regular weekly lectures. Three independent populations were recruited: first year medical students, third year medical students and first year psychology students. <b>Inclusion-/exclusion crit.</b> Inclusion: $\geq 18$ years old Exclusion: none	<b>Main findings</b> Overall, the participants recalled a mean of 33%. The two randomized groups – S and NS conditions, recalled a mean of respectively 35% and 30%. $P=0,036$ . Structured conditions gave a relative increase in recalled items of 17%. Third year medical students had the highest recall (47%), followed by first year medical students (34%) and first year psychology students (25%). $p<0,01$ Structured information was most effective in the group with least medical knowledge.	<b>Checklist:</b> <ul style="list-style-type: none"> <li>• <b>Is the objective clear?</b> Yes</li> <li>• <b>Who was included/excluded?</b> All of the students who wanted to participate was included. Eight participants who did not complete their recall protocol were excluded from the analysis.</li> <li>• <b>Was the groups equal at start?</b> The researches had no background information of the students</li> <li>• <b>Procedure of randomisation?</b> Envelopes marked by the letters A or B were distributed on the students' tables prior to the lectures start</li> <li>• <b>Were the participants/study personnel blinded with regard to group identification?</b> There was a simple randomization. Blinded for participating students.</li> <li>• <b>Were the groups treated equally apart from the "intervention"?</b> Yes. All participants filled out the same protocol.</li> <li>• <b>Primary end point – validated?</b> Yes.</li> <li>• <b>Were the participants accounted for at the end of the study?</b> 8 (3,3%) were excluded. 7 (5%) in the structured groups and 1 (1%) in the non-structured groups.</li> <li>• <b>What was the results? Precision?</b> Structured information increased recall, especially in groups with low prior medical knowledge</li> <li>• <b>Can the results be transferred to practice?</b> In some degree. Recall in the study population may be higher than in the general population (age, education, etc.). Medical knowledge is most likely lower in the general population than in the study population, so the benefit of structuring information may be underestimated.</li> <li>• <b>Were all the outcomes assessed?</b> Yes. The recall protocols were evaluated by two independent raters</li> <li>• <b>Are the advantages worth the disadvantages?</b> Yes. No increase in cost or time using structured information</li> <li>• <b>Is there other literature that supports the results?</b> Yes</li> </ul> <b>What does the authors discuss as:</b> - <b>strengths:</b> first study of the power of information structuring in practice. Other results converge with previous studies - <b>weakness:</b> the use of standardized presentation versus real-life interactions. Representative of the students. <b>Do the results have plausible explanations?</b> Yes. Prior knowledge and experiences affect how we take in new information
<b>Conclusion</b>	<b>Data</b> 355 students were assessed for eligibility. 242 of those were included and randomized. Eight students did not complete their recall protocol. In total 234 students were included in the analysis, of which 97 first year medical students, 39 third year medical students and 98 first year psychology students. <b>Outcome -validation</b> Immediate recall (number of items recalled)	<b>Other important findings</b> The structured conditions were rated significantly higher on quality of communication than the non-structured conditions.	
Structuring discharge information can be a useful tool to improve recall, and it is likely to be most beneficial for patient populations with lower levels of medical knowledge.	<b>Exposure variables</b> Structured (S) or non-structured (NS) videotape of a patient-doctor interaction. <b>Important cofounding factors</b> Prior medical knowledge Current mood Attention level <b>Statistical method</b> sNOVA, non-parametric Mann-Whitney tests, t-test, ANCOVA		
<b>Country</b>	Switzerland and Germany		
<b>Year data collection</b>	2015		

<b>Reference:</b> Papsin E, Haworth R, Chorney JM, et al. Pediatric otoplasty and informed consent: do information handouts improve parental risk recall? Int J Pediatr Otorhinolaryngol 2014; 78: 2258-61.			Study design: RCT
			Grade - quality ++
Objective	Material and method	Results	Discussion/comments/checklist
To assess the effectiveness of information handouts in improving parental risk recall and understanding	<b>Recruiting participants</b> Children and their caregivers, who were at the hospital for a surgical consultation of paediatric otoplasty, were asked to participate in the study after a standard consultation. The study group received a handout before leaving. 12-14 days after the consultation the parents received a phone-call where the study was described, permission obtained and a structured interview was accomplished.	<b>Main findings</b> Overall risk recall for both groups was 48%. The study group had significantly higher recall (p=0,003) than the traditional group. <b>Other important findings</b> The risk recall was significantly higher (p=0,024) in caregivers with higher income compared to caregivers with lower income.	<b>Checklist:</b> <ul style="list-style-type: none"> <li>• <b>Is the objective clear?</b> Yes</li> <li>• <b>Who was included/excluded?</b> All the caregivers who wanted to participate were included. No one was excluded.</li> <li>• <b>Was the groups equal at start?</b> Yes. There were no significant differences between the study and control groups</li> <li>• <b>Procedure of randomisation?</b> An online Research Randomizer program randomized the two groups.</li> <li>• <b>Were the participants/study personnel blinded with regard to group identification?</b> No.</li> <li>• <b>Were the groups treated equally apart from the "intervention"?</b> Yes. All participants received a phone call from a research assistant 12-14 days after the initial consultation</li> <li>• <b>Primary end point – validated?</b> Yes</li> <li>• <b>Were the participants accounted for at the end of the study?</b> Two participants (4%) did not answer on the follow up call.</li> <li>• <b>What was the results? Precision?</b> Written handouts increased recall.</li> <li>• <b>Can the results be transferred to practice?</b> Yes. To use both oral and written information</li> <li>• <b>Were all the outcomes assessed?</b> No. Understanding was not assessed.</li> <li>• <b>Are the advantages worth the disadvantages?</b> Yes. Printed materials are simple and inexpensive tools that can easily be applied in the clinical setting</li> <li>• <b>Is there other literature that supports the results?</b> Yes. Several previous studies have had similar results.</li> </ul> <b>What does the authors discuss as:</b> <b>-strengths:</b> <b>-weakness:</b> timing of the follow-up phone call and selection of participants <b>Do the results have plausible explanations?</b> Yes
<b>Conclusion</b>			
Parental risk recall was improved with the addition of written information	<b>Inclusion-/exclusion crit.</b> Inclusion criteria: Surgical consultation about paediatric otoplasty. <b>Exclusion criteria:</b> Parents not fluent in English. Discussion of other surgical procedures during the consultation.		
<b>Country</b>			
Canada			
<b>Year data collection</b>			
2014	<b>Data</b> 54 participants were asked to participate. Two refused and two were lost to follow up. 50 participants were included in the analysis. Participants were randomized to either traditional oral dialog or oral discussion and a written handout. 25 participants in each group. <b>Outcome -validation</b> Parental risk recall Parental understanding <b>Exposure variables</b> Use of written handouts <b>Statistical methods</b> SPSS: t-test, chi-squared test		

<b>Reference:</b> Lehmann V, Labrie NHM, van Weert JCM, et al. Provider caring and structuring treatment information to improve cancer patients' recall: Does it help? Patient Educ Couns. 2020;103(1):55-62			Study design: RCT
			<b>Grade - quality</b> <span style="background-color: #008000; color: white; padding: 2px;">+++</span>
Objective	Material and method	Results	Discussion/comments/checklist
<p>H1: Does affect-oriented communication style like provider <i>caring</i> enhance trust?          H2: Does affect-oriented communication style like provider <i>caring</i> enhance active recall and recognition of cancer-related treatment information?          H3: Does cognition-oriented style like information <i>structuring</i> enhance recall and recognition?          H4: Are recall and recognition particularly enhances if provider exhibit both <i>caring</i> and <i>structuring</i> communication styles?</p>	<p><b>Recruiting participants</b>          Participants were invited by mass emails sent through an online platform for patient-provider research and a commercial online research platform.</p> <p><b>Inclusion-/exclusion crit.</b>          Inclusion: Cancer patient/survivor or relative/close person of a cancer patient/survivor          Exclusion: None</p> <p><b>Data</b>          161 participants were randomized to one of the four video vignettes          148 participants completed all questions (91%)</p> <p><b>Outcome -validation</b>          Active recall          Recognition          Trust</p> <p><b>Exposure variables</b>          Standard caring          Enhanced caring</p> <p>Standard structuring          Enhanced structuring</p> <p><b>Statistical methods</b>          t-test, chi-squared test, ANOVA, ANCOVA</p>	<p><b>Main findings</b>          Participants exposed for enhanced caring reported significantly higher trust in the provider than the other groups (<math>p=0,010</math>).</p> <p>Overall recall was 56% and recognition was 88%. Neither recall or recognition were significantly enhanced by either caring or structuring.</p> <p><b>Other important findings</b>          Active recall was significantly lower among older participants.</p> <p>Prior medical knowledge had no significant effect on recall</p> <p>Education had a significant effect on recall (<math>p&lt;0,001</math>)</p> <p>Trust was significantly correlated with decreased recall among younger participants (<math>p&lt;0,001</math>)</p>	<p><b>Checklist:</b></p> <ul style="list-style-type: none"> <li>• <b>Is the objective clear?</b> Yes</li> <li>• <b>Who was included/excluded?</b> All participants who finished the survey were included.</li> <li>• <b>Was the groups equal at start?</b> Yes. The four groups did not differ by any background characteristics</li> <li>• <b>Procedure of randomisation?</b> After providing background information in the online platform, participants were automatically randomized into one of four groups</li> <li>• <b>Were the participants/study personnel blinded with regard to group identification?</b> Yes. Both the participants and researches were blinded.</li> <li>• <b>Were the groups treated equally apart from the "intervention"?</b> Yes. All participants watched one of the four video vignettes, and subsequently evaluated the videos and completed a similar questionnaire.</li> <li>• <b>Primary end point – validated?</b> Yes</li> <li>• <b>Were the participants accounted for at the end of the study?</b> Yes. 13 participants did not complete the questions. These did not differ from included participants, except for their age. The discontinued group were older, and consequently more likely to be retired</li> <li>• <b>Can the results be transferred to practice?</b> Yes. May not be generalizable to the whole population.</li> <li>• <b>Were all the outcomes assessed?</b> Yes</li> <li>• <b>Are the advantages worth the disadvantages?</b> Yes</li> <li>• <b>Is there other literature that supports the results?</b> Yes and no. Some of the results support previous results, while other results contradict previous studies.</li> </ul> <p><b>What does the authors discuss as:</b></p> <p><b>-strengths:</b> cancer patients/survivors, the video vignettes resemble real-life situations</p> <p><b>-weakness:</b> most participants were highly educated, the sample size should have been larger, large age-range, higher drop-out of older patient than younger</p> <p><b>Do the results have plausible explanations?</b> Yes. The authors discuss among others that higher trust may cause the patients to blindly trust the physician, and thereby potentially decrease recall and they may take less part of shared decision making.</p>
Conclusion			
Provider caring can strengthen the patient-provider relationship by enhancing trust. Increased trust may impair recall among younger patients. Structuring information did not enhance recall and recognition.			
Country			
Netherlands			
Year data collection			
2017			

<b>Reference:</b> McGuire LC. Remembering what the doctor said: organization and adults' memory for medical information. Exp Aging Res 1996; 22: 403-28.			Study design: RCT
			<b>Grade - quality</b> ++(+) 
<b>Objective</b>	<b>Material and method</b>	<b>Results</b>	<b>Discussion/comments/checklist</b>
To investigate the amount of information that younger and older adults remember over 1 month To examine the effect of information organization on younger and older adults' recall of medical information	<b>Recruiting participants</b> The younger group were students enrolled in a psychology course at one of the three private colleges in the central Ohio area. The older group were recruited from newsletters and announcements at six senior citizen's centers in the central Ohio area <b>Inclusion-/exclusion crit.</b> Inclusion: living independently in the Ohio community, not current or former health professionals Exclusion: cognitively impairing medications, osteoarthritis, self-reported visual and hearing deficits <b>Data</b> 72 participants. 46 in the young group and emergency in the older group. 12 participants did not return for the follow up assessments <b>Outcome -validation</b> Immediate recall 1-week recall 1-month recall <b>Exposure variables</b> Organized and unorganized presentation condition	<b>Main findings</b> Age had no significant effect on recall of medical information Organization of medical information did not have an impact on the amount of information remembered <b>Other important findings</b> Immediately recall was approximately 25%. Recall was higher immediately than after 1-week and 1-month delays Younger adults initially recalled more than older adults. After 1-week and 1-month they remembered equivalent amounts of information	<b>Checklist:</b> <ul style="list-style-type: none"> <li>• <b>Is the objective clear?</b> Yes</li> <li>• <b>Who was included/excluded?</b> All potential participants were included, except for one who failed to meet the inclusion criteria</li> <li>• <b>Was the groups equal at start?</b> There was no significant difference between the two age groups, except for depression (younger&gt;older) and verbal ability (older&gt;younger).</li> <li>• <b>Procedure of randomisation?</b> Participants in both age groups were randomly assigned to one of the videos</li> <li>• <b>Were the participants/study personnel blinded with regard to group identification?</b> Yes. The participant did not know which video they watched</li> <li>• <b>Were the groups treated equally apart from the "intervention"?</b> Yes. After watching the video, the participants completed the same free-recall sequence during each of the three follow-ups.</li> <li>• <b>Were the participants accounted for at the end of the study?</b> Yes. There were 12 drop outs. The younger dropouts occurred because of withdrawal from their psychology course. The older dropouts occurred because of personal or family illness.</li> <li>• <b>What was the results? Precision?</b> Neither age nor structured information affected recall</li> <li>• <b>Can the results be transferred to practice?</b> To some degree. The participants were not real patients.</li> <li>• <b>Were all the outcomes assessed?</b> Yes</li> <li>• <b>Are the advantages worth the disadvantages?</b> Yes</li> <li>• <b>Is there other literature that supports the results?</b> Yes and no. There is research that is both consistent and inconsistent with these results</li> </ul> <b>What does the authors discuss as:</b> <b>-strengths:</b> few studies of how time and age affect recall <b>-weakness:</b> Did not examine patients' recall of medical information about a health condition that they had. <b>Do the results have plausible explanations?</b> Yes. Authors discuss a negative relation between the amount of information presented and the amount recalled. Younger people have a larger working memory capacity and therefore they had higher immediate recall than the older participants
<b>Conclusion</b>			
In general, younger and older adults remembered equivalent amounts of medical information Organization of medical information did not have an impact on the amount of information remembered			
<b>Country</b>			
USA			
<b>Year data collection</b>	<b>Important cofounding factors</b>		
1996	<b>Statistical methods</b> Pearson product-moment correlation coefficient, ANOVA		

## Appendix

### Appendix 1: Information sheet to patient

#### Vil du delta i forskningsprosjektet

##### *”Hva sa legen?”*

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å undersøke hva pasienter husker og forstår av informasjonen de får ved utskriving. I dette skrevet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

##### **Formål**

Formålet med prosjektet er å vurdere gjenkalling og forståelse av informasjon gitt ved utskriving fra observasjonsposten. Vi ønsker å se nærmere på hvor mye av informasjonen som huskes og hvordan den blir forstått av pasienten. Dette kan brukes videre til å vurdere kvaliteten på kommunikasjonen, og eventuelt muligheter for forbedring.

##### **Hvem er ansvarlig for forskningsprosjektet?**

Ansvarlig for forskningsprosjektet er Eirik Hugaas Ofstad, konstituert avdelingsoverlege ved observasjonsposten Nordlandssykehuset (NLSH) og førsteamanuensis ved Universitetet i Tromsø (UiT).

##### **Hvorfor får du spørsmål om å delta?**

Vi ønsker deltakere som blir skrevet ut av observasjonsposten til hjemmet. Vi trenger ca. 30 deltakere. For å være med i studien må man være fylt 18 år og ha gode norskkunnskaper. Deltakere kan ikke være innlagt på sykehus i perioden mellom utskriving og intervjuet.

##### **Hva innebærer det for deg å delta?**

Hvis du velger å delta i prosjektet, innebærer det at utskrivingssamtalen på sykehuset filmes og at du deltar på ett telefonintervju to uker etter utskriving. Utskrivingssamtalen vil foregå som normalt, der du får både muntlig og skriftlig informasjon fra en lege på avdelingen. Intervjuet vil være med student Kjersti Østen, og det vil inneholde spørsmål om oppholdet på sykehuset og om informasjonen du fikk ved utskriving.

##### **Det er frivillig å delta**

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

##### **Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger**

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrevet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

- Det er kun prosjektgruppen som har tilgang til dine svar fra intervjuet. All bruk av dine resultater vil bli anonymisert, og du som deltaker i prosjektet vil ikke kunne gjenkjennes i studien
- Navnet og kontaktopplysningene dine vil bli erstattet med en kode som lagres på egen navneliste adskilt fra svarene fra intervjuet.
- Dataen vil bli lagret på NLSH sin forskningsserver, hvor kun prosjektgruppen har tilgang med brukernavn og passord. Videoopptak vil bli lagret på en kryptert harddisk som vil bli oppbevart i ett låst skap på ett låst kontor på sykehuset
- Du kan når som helst ta kontakt om du har noen spørsmål eller ønsker å trekke deg.

##### **Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?**

Prosjektet avsluttes august 2022. Ved prosjektslutt vil personopplysninger, videoopptak og innsamlet data om deg blir slettet.

##### **Dine rettigheter**

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rett personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

##### **Hva gir oss rett til å behandle personopplysninger om deg?**

Vi behandler opplysninger om deg basert på ditt samtykke.

Prosjektet er godkjent av personvernombudet ved Nordlandssykehuset.

##### **Hvor kan jeg finne ut mer?**

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Eirik Hugaas Ofstad på epost [ehof@nlsh.no](mailto:ehof@nlsh.no) eller telefon 91185581
- Vårt personvernombud: Personvernombudet ved Nordlandssykehuset

Med vennlig hilsen

Eirik Hugaas Ofstad

## Appendix 2: Information sheet to health worker

### Informasjonsskriv om forskningsprosjektet

#### *”Hva sa legen?”*

Dette er et informasjonsskriv til deg som helsepersonell om et forskningsprosjekt hvor formålet er å undersøke hva pasienter husker og forstår av informasjonen de får ved utskriving. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

#### **Formål**

Formålet med prosjektet er å vurdere gjenkalling og forståelse av informasjon gitt ved utskriving fra observasjonsposten. Vi ønsker å se nærmere på hvor mye av informasjonen som huskes og hvordan den blir forstått av pasienten. Dette kan brukes videre til å vurdere kvaliteten på kommunikasjonen, og eventuelt muligheter for forbedring.

Studien består av to deler. Første del er videooptak av utskrivingssamtalen. Andre del vil foregå to uker senere. Student Kjersti Østen vil da ringe opp pasientene og foreta et intervju for å undersøke hvor mye de husker av informasjonen de fikk.

#### **Hvem er ansvarlig for forskningsprosjektet?**

Ansvarlig for forskningsprosjektet er Eirik Hugaas Ofstad, konstituert avdelingsoverlege ved observasjonsposten Nordlandssykehuset (NLSH) og førsteamanuensis ved Universitetet i Tromsø (UiT).

#### **Hvorfor får du spørsmål om å delta?**

Studien skal omhandle pasienter som blir skrevet ut av observasjonsposten til hjemmet. Helsepersonell som er med på utskrivingssamtalen må også samtykke til å være med i studien.

#### **Hva innebærer det for deg å delta?**

Hvis du velger å delta i prosjektet, innebærer det at utskrivingssamtalen som du deltar på filmes. Utskrivingssamtalen vil foregå som normalt, der pasienten får både muntlig og skriftlig informasjon fra en lege på avdelingen. Student Kjersti Østen vil være ansvarlig for å informere pasienten om forskningsprosjektet, hente samtykke og filme samtalen.

#### **Det er frivillig å delta**

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

#### **Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger**

Vi vil bare bruke videooptaket av om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personverregelverket.

- Det er kun prosjektgruppen som har tilgang til videooptaket.
- Dataen vil bli lagret på NLSH sin forskningsserver, hvor kun prosjektgruppen har tilgang med brukernavn og passord. Videooptak vil bli lagret på en kryptert harddisk

#### **Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?**

Prosjektet avsluttes august 2022. Ved prosjektslutt vil all data bli slettet.

Prosjektet er godkjent av personvernombudet ved Nordlandssykehuset.

#### **Hvor kan jeg finne ut mer?**

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Eirik Hugaas Ofstad på epost [ehof@nlsh.no](mailto:ehof@nlsh.no) eller telefon 91185581
- Vårt personvernombud: Personvernombudet ved Nordlandssykehuset

Med vennlig hilsen

Eirik Hugaas Ofstad

### **Appendix 3: Main message**

*Questions are asked directly after the discharge encounter.*

*Til pasient: Hva synes du var den viktigste informasjonen du fikk av legen?*

*Til lege: Hva var den viktigste informasjonen for deg å formidle til pasienten?*

### **Appendix 4: Health literacy questionnaire**

*Questions are asked to the patients before discharge. Each question is scored on a scale 1-5.*

Hvor ofte har noen (f.eks. familie, venn, helsepersonell) hjulpet deg med å lese/forså papirer fra sykehuset?

- 1 = hele tiden, 2 = ofte, 3 = noen ganger, 4=sjeldent, 5 = aldri

Hvor ofte har du problemer med å forstå/lære om dine medisinske tilstander på grunn av vanskeligheter med å forstå skriftlig informasjon?

- 1 = hele tiden, 2 = ofte, 3 = noen ganger, 4=sjeldent, 5 = aldri

Hvor sikker føler du deg på å fylle ut helseskjema alene?

- 1 = veldig usikker, 2 = litt usikker, 3 = verken eller, 4=ganske sikker, 5 = veldig sikker

### **Appendix 5: Interview guide**

#### **Orientering**

*Dette er medisinstudent Kjersti Østen fra Nordlandssykehuset som ringer. Snakker jeg med .....? Du sa deg villig til å delta i studien "Hva sa legen?" for to uker siden, og jeg ringer nå for å stille deg noen spørsmål om samtalen du hadde med legen ved utskrivelse fra sykehuset. Det tar ca. 20 minutter.*

**Har vært innlagt på sykehuset på nytt de siste 14 dagene?**

#### **Hoveddel**

**Fortell det du husker av informasjonen du fikk på sykehuset.**

*Dersom deltakeren ikke husker eller forteller lite, så kan disse spørsmålene/stikkordene være til hjelp.*

- Hva var årsaken til at du kom på sykehuset? Hva sa legen at det feilte deg? Hvilken diagnose fikk du?
- Hva var det legen fortalte om din diagnose/tilstand?
- Hva sa legen angående medisiner eller annen behandling? (type, varighet, dose, indikasjon, bivirkninger)
- Fikk du noen instruksjoner, råd eller videre plan av legen? (oppfølging, livsstilsendringer, faresignaler)



**Når du tenker tilbake på samtalen du hadde med legen, hva er ditt inntrykk av den viktigste informasjonen du fikk?**

**Hvordan var det å komme hjem fra sykehuset?**

- Stikkord: Hvordan opplevde du overgangen fra sykehus til hjemmet? Usikkerhet, trygghet, osv.?

**Hvordan opplevde du informasjonen du fikk på sykehuset?**

- Stikkord: Var det noe av det legen sa som du ble usikker på om du hadde forstått?
- Hva var det som var vanskelig å forstå?
- Følte du at du forsto all informasjonen du fikk?
- Hva tenker du om mengden informasjon du fikk? Overveldende, mangelfullt, osv. Savnet du noe informasjon? Har du prøvd å finne mer informasjon på egenhånd?
- Har du fått hjelp fra noen (f. eks. familie, venner) for å forstå noe av informasjonen du fikk på sykehuset?

**Har du noen tanker om hvorfor det var vanskelig å få med seg og forstå informasjonen? (evt. Hvorfor du har fått med seg så mye?)**

- Hva mener du kunne vært gjort bedre?

### **Avslutning**

Er det noe mer du har lyst til å fortelle om fra utskrivningssamtalen?

