Patients' Participation in Decisions in an Anaesthesia Healthcare Setting

A survey of patients' and personnel's attitudes and experiences

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A survey of patients’ and personnel’s attitudes and experiences

Patienters medverkan i beslut inom anestesivården

En undersökning av patienters och personals attityder och erfarenheter

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Abstract
A need for the personnel at the Anaesthesiology and Intensive Care Unit at Danderyd Hospital to better understand their patients' experiences and attitudes towards participation in their care was identified by the Clinical Innovation Fellowship program at Centre for Technology in Medicine and Health. This study aimed to provide the Anaesthesiology and Intensive Care Unit with information on patients and personnel's experiences and attitudes towards patients' participation; this would allow them to understand how they should focus their resources. A cross-sectional and group comparing survey was performed at the Anaesthesiology and Intensive Care Unit in the spring of 2016. A total of 55 patients scheduled for surgery and 38 from the personnel at the Anaesthesiology and Intensive Care Unit participated. The results show there is high overall satisfaction among the participants of their experiences of patients' participation. The majority of the patients wanted to be passive in decisions, no connections between personal characteristics and preferred level of participation was found. Patients who did not felt they had been able to participate enough also felt uninformed. Furthermore, physicians seemed to have better opportunities to include patients in decisions compared to the nurses. The healthcare systems should work to adapt the care for each individual patient and to provide them with information suitable for the individual in order to support patients' participation; IT-systems could be one way of doing this. Future studies should further investigate which factors could influence patients' participation and how healthcare services and technology could be designed in order to support patient participation.

Keywords: patient participation, control preference scale, information, anaesthesiology, patient and personnel experience
Sammanfattning


Nyckelord: patient participation, control preference scale, information, anaesthesiology, patient and personnel experience
Foreword
This master thesis has been performed at the Royal Institute of Technology (KTH) in the area of technology and health.

I would like to thank everyone who has been of help during this master thesis, the personnel at Danderyd hospital which let me survey them and their patients; and the clinical fellows from CTMH who identified the need for this study and introduced me at Danderyd hospital.

I would specially like to thank my supervisor Peta Sjölander from KTH for all her time and continuous support from the beginning to the end during the work of this thesis.

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1 Introduction

Today’s society is undergoing constant change; for example, the population of Stockholm is growing and the advancements of different services and technologies are continuously developing. Healthcare plays an important part in society and Stockholm County Council (SLL) is changing the care in order to satisfy the populations’ expectations [1]. In line with these changes, Sweden introduced a new Patient act on 1st January 2015 [2] which aims to “strengthen and clarify the position of the patient and to promote patient privacy, self-determination and participation” [3]. This new regulation is in line with the latest years’ work within the Swedish healthcare system where the patients’ care chain should be created from the individual patients’ preferences and needs [4]. In line with the new regulations of including patients more in the healthcare; there are arguments which support the idea that not only the care but also medical technology should be developed with the patients’ needs and expectations in mind [5].

Danderyd Hospital is one of the largest emergency hospitals in Sweden; it is specialized in the areas internal medicine; cardiology; orthopedics; obstetrics and gynecology; surgery and urology [6]. Danderyd Hospital is working towards becoming a hospital which operates as a more person-centred facility, this means that they use the resources from each individual person and create a partnership between the care provider and the patient. Danderyd Hospital uses the National Patient Survey in order to measure satisfaction among the patients. Overall their patients are satisfied with the provided care; however, the hospital wants to improve its work to include the patients in its care and to improve the communication with their patients because these are the two areas where the patients are least satisfied [7].

During the autumn of 2015 the Clinical Innovation Fellowship Program from the Centre for Technology in Medicine and Health (CTMH) was carried out at the Anaesthesiology and Intensive Care Unit at Danderyd Hospital. CTMH is based in Flemingsberg and is a cooperation between Karolinska Institutet (KI), the Royal Institute of Technology (KTH) and SLL. The Anaesthesiology and Intensive Care Unit at Danderyd is taking care of patients which are undergoing surgery, are critically ill or patients who require intensive care; examples of surgeries they are involved in are urology; orthopedics; obstetrics; gynaecology; ear, nose and throat; and dental care [8]. In addition, the Anaesthesiology and Intensive Care Unit is responsible for the Anaesthesia clinic. At the Anaesthesia clinic medical personnel meets with the patient prior to its surgery in order to assess the patient and decide which anaesthesia method should be used during the surgery. However, not all patients visit the Anaesthesia clinic before surgery; persons who are considered to be healthy and persons scheduled for smaller procedures are assessed via a health declaration which the patient has answered at home [9]. The group of clinical innovation fellows from CTHM identified different areas at the Anaesthesiology and Intensive Care Unit which were in need of more research or improvements; one of these areas was that the personnel wanted to know more about expectations and experiences of their patients. The personnel recognized that technology and services in the society are changing which they believe can change the patients expectations
regarding healthcare; in addition the personnel needs more information about their patients in order to adapt to the new patient act in the best way possible.

1.1 Aim
The Anaesthesiology and Intensive Care Unit has previously only had time for shorter surveys and wanted to gain more information from the patients regarding their contact with the hospital and specifically the patients’ participation in their care. The aim of this study was to better understand where the care unit needs to focus its resources by surveying patients’ and personnel’s experiences and expectations in the area of patient participation. This approach would allow for the possibility to find future solutions which could help the healthcare system to meet the new demands from society and its inhabitants.

This information would provide the personnel and management at the Anaesthesiology and Intensive Care Unit with information concerning patients’ experiences on their participation in their care as well as the personnel’s thoughts on patients’ participation. The collecting of information from the two different groups, i.e. patients and personnel, could help to better understand the entire situation concerning patient participation. This information allows the Anaesthesiology and Intensive Care Unit to continue its work to improve the care and to better adapt to the patients’ and personnel’s needs. In addition, it could help them to adapt to the new patient act were the importance of including the patients in their care is stressed.

Three research questions have been formulated in order to reach the aim of this thesis:

i. Is it possible to identify characteristics within patient groups which connect to their preferred level of participation in their own healthcare decisions?

ii. How is patient participation within the area of anaesthesia experienced by two different groups: patients and personnel?

iii. Are there factors identifiable within the care experience which either facilitate or hinder the participation of patients in their care?

1.2 Delimitations

i. The new patient act covers a large area of the healthcare sector. This thesis, however, focuses on the patients’ participation in their care, and more specifically their participation in anaesthesia care.

ii. The Anaesthesiology and Intensive Care Unit has patients at different places in Danderyd Hospital. This study only surveys patients who are undergoing surgery at the central operational unit at Danderyd Hospital. These patients undergo surgical, urological or orthopaedic surgeries.

iii. There are three major types of professionals hired at the Anaesthesiology and Intensive Care Unit, anaesthesiologist, anaesthesia nurses and assistant nurses. This study only surveys the anaesthesiologists and anaesthesia nurses as they are the two professions which most often disclose information to the patients and make decisions about treatments.
2 Background

It is commonly thought that patients today have a greater access to information about health issues compared to how it was in the past; this is probably due to an increased internet access among the public [10]. Internet enables people to research information they think is important and provides them with the possibility to make inquiries at a time when it suits them; in addition, the internet allows people to get in contact with others in order to share their experiences and knowledge [11]. In a healthcare context, this more easily accessible health information will let patients get more information about their health and different treatment options.

More easily accessible information enables people to gain more information and thus become "informed patients". This development has also created a possibility for the patients to become more involved in their care [10]. Patient involvement or patient participation, are concepts which are perceived to be complex depending on several factors. First, there are different ways in which patients may become involved in their care; for example, it could be that patients should have the possibility to make choices; or that they should be co-producers of their care, meaning that they should be included in the design of different healthcare services [12] or that they should be involved as designers of new technology and thus become part of the process of medical technology development [13]. A second reason for patient involvement being perceived as complex is because any patient might want to be involved in her or his care in different ways depending on the situation [14]; it is not common for patients to be fully committed to involvement or completely lacking of any desire of involvement, the greater part instead belong to a scales in-between these two extremes [10]. In addition, there are differences between how each individual patient wants to be involved [15] and these differences depend on a variety of factors [16]; these examples adds to the complexity of the concept of patient participation.

Patient participation is a concept which has existed for several years; for example, in the report Crossing the Quality Chasm written by the Institute of Medicine they stress the need to give patients the control over how much they want to decide about their care when new healthcare systems are engineered [17]. Furthermore, since the seventies WHO have encouraged different stakeholders responsible for healthcare systems to increase the engagement of patients in their care [18]. Today, the concept of patient participation is increasingly being viewed as more and more important in healthcare systems around the world [14, 19], and Sweden is not an exception. The new patient act shows that the Swedish government wants to create a healthcare system where the patient has more influence.

Currently, the Swedish healthcare system is more focused and responsive to the biomedical-technological aspects of the healthcare compared to the human aspects which could be regarded as a cause of concern for the Swedish healthcare system [20]. In connection to this concern, there exists a challenge to create an environment within the healthcare system that both supports the clinical and technological needs as well as the human needs [21]. With this in mind, it is important to take action on issues which are related to organization, management and institutional changes within the healthcare system [20]. The new patient act could potentially be seen as a
step towards a healthcare system where human needs are recognized as equal to technological needs. This could be the case since the new law clearly states that patients should have more influence over their care compared to what they previously have experienced; for example, it is more clear in the new patient act that patients should receive information on their health status and information about methods for examinations, care and treatment [3]. Furthermore, the new patient act is a step towards a healthcare system where the patients’ care chain is being created from the individual patients’ preferences and needs [4], and not from the diagnosis or the healthcare personnel’s perspective.

### 2.1 Engineering for the Healthcare System

In order to create solutions for healthcare, there is a need to gather information about how the people being affected by the services and technologies experience these services and technologies. Thus, engineers working within the area of healthcare will need to have a closer involvement with the users, i.e. the people benefiting from the technology, in order to better understand the requirements and expectations of those users. By having closer interactions it is possible for engineers to find opportunities for innovations within existing healthcare systems; which will look only at the needs of the individuals instead of looking into the needs of the entire community. Furthermore, it is important to develop technology which can facilitate personal interactions between healthcare personnel and those benefitting from that technology. In the article *Engineering innovation in healthcare: technology, ethics and persons*, the author concludes that engineers within the healthcare “need to be taught to prioritize persons rather than technology”. [22]

Patients are seldom included in the process of finding or developing innovations in healthcare; they are often involved in the test phase but not earlier in the crucial development phase [13]. It is important to include the patients in the innovation process since it is the patients’ needs that create the foundations for innovation [13]. Furthermore, patients should be included in the research processes; by doing this it could be possible to direct the research towards areas which patients think could be useful [23]. Including patients in innovation and research are two examples of how the medical technology industry could use knowledge from patients in order to create products with a high value for the end-users. This could be important seeing that a high constraint on the economy in the healthcare system forces companies to better adapt to their customers [24]. By developing medical technology from the patients’ needs and expectations it could be possible to create a better outcome for the individual, communities and global health [5]. With this in mind, patients’ perspectives and their input is important information for the development of medical technology.

### 2.2 Patient Participation

As mentioned earlier there is an increased attention on the process of involving patients in their own care; governments want patients to participate and to be able to make decisions about their own care. In the book *Crossing the Quality Chasm* the Institute of Medicine recommend that patients and care providers should work together and that the patients should be the source of the control to a degree of their
own choosing [17]. There are different arguments for why patients should participate in their care. One reason for why the healthcare system should get patients to participate is because participation is seen as a human right and that a patient should be able to express a self-determination [25]. Another reason is that there are suggestions that patients which are involved and participate in their care may have a better health outcome [15, 26, 27], and increased patient involvement could enhance patient safety [25]. Research has also shown that patients that are participating in their care receive more information about their care from their physician [28], and more information to the patients is one of the aims with the new Swedish patient act.

A potential problem with patient participation specific to Sweden is that the laws regulating the patients’ rights are not always followed. The Swedish Agency for Health and Care Services Analysis did a survey in 2014, before the new patient act was implemented, and found that current laws regulating patients’ rights were not always fulfilled [29], which could be a cause for concern. Many of the parts in the new patient law have previously existed in other regulations; however, they are now included in the new patient law in order to clarify for all stakeholders which demands exists within the healthcare system [29], this law could potentially overcome the problem of low adherence.

Even though patient participation is seen as a beneficial opportunity for the individual person, there are concerns that patient participation might not be as beneficial as it most commonly is being described. One example of this is that there exist few studies which investigate the connection between patient participation and a better health outcome, and in a review study of patient participation in a primary care setting there was no health outcome benefits of patient participation [30]. Other research has also shown that when policies advocates for more engaged patients in decisions the length of stay at hospitals and the costs increases [31], and it is unlikely that patient involvement can lead to greater patient safety [32]; these findings are in contrast to what is commonly stated when patient participation is up for discussion. Additional concerns connected to patient participation are the lack of a clear definition [30], adding to the complexity of patient participation as a concept.

In addition, there exists gaps between what is considered an ideal participation and the actual patient participation [18].

2.3 Patient Participation and Information Systems

In order for a patient to be able to participate in his or her care, and to be included in the process of decision making there are some parts which are important to recognize. First, patients need information; second, patients need to think about what their goal is with the treatment; and third, they have to communicate and share this with their care provider [33]. One way to increase patient participation is the so called shared decision making model, where physicians provide the patient with information from which the patient and the physician together can agree on a treatment [18]. Shared decision making is thus an example of how information can facilitate patient participation.
In recent years IT-services that enable patient and healthcare provider communication have become more common; there are thoughts that these kinds of IT-services could enhance the patients participation and involvement in their care [26]. A form of shared decision making among healthcare personnel and patients is the use of the electronic health records. When a physician is using the computer during a patient visit in order to document data in the electronic health record, it has been shown that the patient-physician communication is affected negatively from the patients perspective [34]. One potential way to overcome this problem is to invite the patient to look at the screen together with the physician; this can lead to improved patient-physician communication, patient participation and shared decision making [35]. Additional support to this is that when consultation rooms were re-designed in a way which enabled patients to see the computer screen, a study showed that patients reported an enhanced experience of the information the physician shared with them from the screen [36]. This illustrates how medical technology, and the design of it, can be used in order to increase patient participation.

It is not only important to design and adapt solutions for the patients, but also for the personnel within the healthcare system. A study investigating the satisfaction of electronic health records among clinicians and information technology professionals showed that there exists a gap between these two groups, clinicians were not as satisfied as the other group. The authors concluded from this that the design of electronic health records should be designed to more closely meet the needs of the clinicians [37].

2.4 Quality and Satisfaction from the Patient Perspective
When the quality of the care is evaluated with the aim to improve it, it is important to include the perspective of the patients since they are the ones receiving the care; patients should be able to share their views of what they perceive as quality [38]. Furthermore, it may not always be the case that patients perceive quality in the same way as medical personnel; this is another reason for why patients’ views on quality should be investigated. According to a study conducted in the USA, having respect for the patients’ values, preferences and expressed needs is one area identified as a quality indicator for patients; this was identified by examining patients experiences and needs [39]. Respect for patients values, preferences, and expressed needs are all important aspects in order to get patients to participate; yet, it has been shown that a high degree of patient satisfaction does not automatically translate to a high degree of patient participation [40].

2.5 Anaesthesia
Compared to other specialties within the healthcare system, anaesthesia is different because the patients are often asleep when the anaesthesiologist performs his or her work; this is important to remember when patients are asked about their involvement in their anaesthesia. For example, few patients know what role an anaesthesiologist has outside the operating room; which could be due to the fact that anaesthesiologists have little contact with awake patients compared to other specialists [41]. Similarly, one study showed that 25% of patients felt they had not
received enough information about the benefits of using anaesthesia; this result was unexpected, possibly because anaesthesiologists overestimate the general knowledge the public have regarding anaesthesia [42].

Studies in the field of anaesthesia have shown that the patients want to be involved in the decision making process connected to their anaesthesia, practicing so called shared decision making [43]. In addition, patients that are asked if they would like to be anesthetized or have a spinal anaesthesia felt that their opinions were respected and felt positive that they were given a choice [44]. However, it is important to remember that patients undergoing surgery are in a dependent situation. A study has found that patients who are awake during surgery feel very dependent on their care providers since they are trusting them to do what is best for them as a patient; the authors conclude that it is important for the care providers to recognize this dependence and to care for the patient on a personal level [45].
3 Method
This thesis used a descriptive and quantitative method in order to describe how the current situation at an anaesthesiology unit within a large general hospital is experienced by the patients and personnel, and what subject preferences were in connection to the concept of patient participation. The method used to gather the results was a cross-sectional and group comparing survey.

3.1 Survey Design
With the aim of creating a survey which would answer the specific research questions for this thesis, a literature study on the area of patient participation was conducted. The research questions were designed by the researcher from the literature study, or reworked from existing examples available in literature in order to ensure a high validity. In order to create survey questions that would answer the research questions of the thesis, a measurement matrix was constructed. A measurement matrix describes how the different survey questions are connected to the main concepts of the study and helps to create a survey that best answers the research questions [46].

When trying to measure patient satisfaction within any area, an evaluation of the patients’ own experiences of healthcare is important, because their satisfaction depends on what they have themselves experienced [39]. There are today discussions on whether patient satisfaction or experience should be measured when the hospitals evaluate their quality; research has shown that more meaningful information about the quality of the care can be collected by surveying patient experience instead of patient satisfaction [47]. Because of this, the focus of the questions in this thesis is on how the patients have experienced different aspects of their care in order to gather as meaningful information as possible.

In this study, the participants, i.e. patients and personnel, have been included in the design of the questions; which is recommended by existing literature [48]. This ensures a high content validity which is important in order to ensure that the questions used are characteristic for the area which is being investigated [46]. The questions in the survey were designed to ask specifically about the participants' experiences of and expectations on anaesthesia.

3.1.1 Patient Survey
The patient survey consisted of 15 questions. Four of the questions aimed to identify the characteristics of the participants. The other 11 aimed to investigate the patients’ experiences and attitudes towards participation in the anaesthetising care; two of these were open-ended in order to allow participants the possibility to add information they thought to be important for this area. The questionnaire which was handed out to the patients can be found in Appendix A.

Three of the questions were taken from the National Patient Survey, which is a recurring survey investigating the patients' views on the quality of the Swedish healthcare coordinated by the Swedish Association of Local Authorities and Regions [49]. The questions from the National Patient Survey use a scale where the participants have five options to choose between, a so called Likert scale which
frequently is used in surveys. The options in this survey ranged from Strongly agree (Ja, helt och hållet) to Strongly disagree (Nej, inte alls). Likert scales allow the participants to grade how much they agree and do not force them to choose between agreeing and disagreeing. All questions with the Likert scale design included an additional option where the patients could choose Have not taken stand (Har ej tagit ställning). In order to design a coherent questionnaire, the other questions evaluating patients’ attitudes and experience on specific areas were formulated in the same way.

The Control Preference Scale is a measurement used to identify patients preferred level of participation in decision making within the healthcare setting; it consists of a five level scale where the patients’ choose which level they most prefer [50]. The five different levels can be seen in Table 1, alternative a) and b) are grouped together as active patients, c) is for collaborative patients and d) and e) are grouped together as passive patients. The Control Preference Scale was used as one of the questions in order to investigate patients preferred level of participation in decision making connected to their anaesthesia care.

Table 1 The five different levels patients can choose between in the Control Preference Scale [51]

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<tr>
<td>a)</td>
<td>I prefer to make the final decision</td>
<td>Active</td>
</tr>
<tr>
<td>b)</td>
<td>I prefer to make the final decision after seriously considering my physician/nurse opinion</td>
<td></td>
</tr>
<tr>
<td>c)</td>
<td>I prefer that my physician/nurse and I share responsibility for the decision</td>
<td>Collaborative</td>
</tr>
<tr>
<td>d)</td>
<td>I prefer that my physician/nurse makes the decision after he/she seriously considers my opinion</td>
<td>Passive</td>
</tr>
<tr>
<td>e)</td>
<td>I prefer my physician/nurse to make the decision</td>
<td></td>
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Before the questionnaire was handed out it was tested on five patients in order to investigate if they understood the questions correctly. After this process, minor changes were made in the formulation of the questions to clarify the meaning for patients.

3.1.2 Personnel Survey
The personnel survey was constructed to mirror the questions in the patient survey in order to be able to discuss similarities or differences between the two groups. Physicians and nurses were given the same survey but asked to state their profession in the first question. The questionnaire which was handed out to the personnel can be found in Appendix B.

3.2 Selection of Participants
All results from patients and personnel were collected at Danderyd Hospital in Stockholm. The patient and personnel results were gathered during a two week period in April 2016; this two week period included the pilot testing of the survey.
The patients that participated in the study were first asked to participate when they came to the hospital the morning for the day of their surgery. When they had been informed of the nature of the study they answered the questionnaire, either in the waiting room or in their assigned hospital bed. Before the patients were asked to participate the personnel on the ward were consulted on whether or not the specific patient would be a good candidate for the study; all patients who the personnel though would be a good candidate were asked to participate. Examples of reasons for why a patient was not thought to be a good candidate was that they would not have enough time to answer the survey before they were transported to surgery or that they did not speak Swedish. Each of the patients participating in this study was healthy enough to travel by themselves to the hospital on the day of their surgery; they had thus not been staying at the hospital on the night before their surgery. A total of six days was spent on gathering results from patients with the aim to gather as many respondents as possible. The minimum number of participants was set to 40 in order to increase the chance of finding trends in the data but also to be able to ensure anonymity for the participants; if 40 would not have been reached during the two week period assigned for gathering of the results the time would have been extended.

All personnel that participated in the study were working on the Anaesthesiology and Intensive Care Unit. The personnel included in this study were anaesthesiologists and anaesthesia nurses who in their work had contact with patients who were undergoing surgery at the central operational unit at Danderyd Hospital. The surveys to the personnel were handed out on two different meetings, one meeting were anaesthesia nurses attended and another meeting were anaesthesiologists attended; before the surveys was handed out the participants was informed on the aim of the study. The personnel were asked to fill in the survey and to hand it in during the next couple of days, allowing them to answer the survey at a time of their own choosing. The majority of the personnel at the Anaesthesiology and Intensive Care Unit, but not all, participated in this study; it was limited to the number of participants on the two separate meetings. Not known how many from the personnel would attend these meetings and having the time to answer the survey, the minimum limit was set to 20 of which 10 should have been anaesthesia nurses and 10 should have been anaesthesiologists.

### 3.2.1 Ethical Considerations

All participants received written and oral information about the study before they were asked to participate. The participants received information about the aim of the study; what it meant for them to participate; how the gathered information would be used; that all gathered information was anonymous; and that participation was voluntary.
3.3 Data analysis
Excel was used for data entry and for analysing the results. Responses from the Likert scales were converted to numbers; *Strongly agreed* was assigned number 5 and *Strongly disagree* was assigned number 1. The three intermediate options had no further explanations in the survey and were entered as number 2, 3 or 4 in the data entry. However, in the result section these numbers are presented in text format; a representation of how the numbers were converted to text can be seen in Table 2. All answers from the other questions were entered as text. If participants choose not to answer a specific question it was compiled as *Have not responded to the question*, which is different from if the participants had chosen to answer *Have not taken a stand*.

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<tbody>
<tr>
<td><strong>Strongly agree</strong></td>
<td>5</td>
</tr>
<tr>
<td><strong>Agree</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
<td>3</td>
</tr>
<tr>
<td><strong>Disagree</strong></td>
<td>2</td>
</tr>
<tr>
<td><strong>Strongly disagree</strong></td>
<td>1</td>
</tr>
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The open-ended questions was entered as text and not changed from how the participants had written their answers; in order to find trends in these answers they were categorized by the researcher. The answers to the open-ended questions presented in the result section have been translated from Swedish to English by the researcher.

No personal data was collected or stored in order to ensure anonymity for the participants.
4 Results

4.1 Characteristics of the Participants

4.1.1 Patients
A total of 56 patients were invited to participate in the study; of these, 55 chose to take part. Of these 55, 39 were men and 16 were women. Participants belonged to the seven age groups 18-30, 31-40, 41-50, 51-60, 61-70, 71-80 and 81-90 years. As can be seen in the histograms in Figure 1, overall the women were younger than the men. Forty-one (74.5%) of the patients had been at the Anaesthesia clinic and met with an anaesthesiologist prior to their surgery and the remaining 14 had not.

4.1.2 Personnel
A total of 38 members of the personnel participated from the Anaesthesiology and Intensive Care Unit. This group was further sub-divided into two groups, anaesthesiologists and anaesthesia nurses. Eighteen persons were in the anaesthesiologists group and 20 were in the anaesthesia nurses group. All subjects were aged between 20 and 65 years. Each subject was recorded as belonging to one of five age-ranges: 20-30, 31-40, 41-50, 51-60 and 61-65. Exactly half of the participants in the both respective groups were 40 and below and the rest above. For the anaesthesiologists group the majority was in the age 31-40 and in the anaesthesia nurse group the majority was aged 20-30. Figure 2 shows the distribution of the ages in the groups: anaesthesiologists and anaesthesia nurses.
4.2 Preferences for Participation

4.2.1 Patients

If it was possible in their specific situation, 32 (58.2%) of the patients stated they would like to, in collaboration with a physician or nurse, decide whether or not they should be awake or asleep during surgery. Seventeen (30.9%) would not want to participate in this decision and six (10.9%) had not taken a stand or did not think that the question was relevant for their situation.

The responses from the Control Preference Scale showed that 12 (21.8%) of the patients rated themselves as active, 16 (29.1%) as collaborative and approaching half of the patient group (n=25; 45.5%) regarded themselves as passive. Two (3.6%) of the participants did not answer the question. The full distribution of the answers is seen in Table 3. Little more than half of the women, 10 of 18 (62.5%), responded that they wanted to be passive, which is a higher number compared to the men where only 15 of 39 (38.5%) responded that they wanted to be passive. No trend between age and preferred level of participation was found.

Figure 2 The left histogram shows the age distribution among the physicians and the right histogram shows respective histogram for the nurses.
Table 3 Distribution of the patients answers in the Control Preference Scale

<table>
<thead>
<tr>
<th>Distribution of the patients answers</th>
<th>Distribution of grouped answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer to make the final decision</td>
<td>n=2</td>
</tr>
<tr>
<td>I prefer to make the final decision after seriously considering my physician/nurse opinion</td>
<td>n=10</td>
</tr>
<tr>
<td>I prefer that my physician/nurse and I share responsibility for the decision</td>
<td>n=16</td>
</tr>
<tr>
<td>I prefer that my physician/nurse makes the decision after he/she seriously considers my opinion</td>
<td>n=14</td>
</tr>
<tr>
<td>I prefer my physician/nurse to make the decision</td>
<td>n=11</td>
</tr>
<tr>
<td>Have not responded to the question</td>
<td>n=2</td>
</tr>
</tbody>
</table>

All of the patients that rated themselves as active (n=12) answered that they wanted to be part of the decision whether or not they should be awake or asleep during surgery; of these 12 active patients two were women and 10 were men. In the group of the 25 passive patients, 11 had responded e) (*I prefer to leave all decisions regarding treatment to my physician/nurse*); of these 11, the majority (n=10) also answered that they wanted the physician to decide if they should be asleep or awake and one had not taken a stand. The correlation between the answers to the Control Preference Scale, only including the 53 patients that answered the question, and the question regarding if the patient would like to be part of the decision and decide if they should be awake or asleep during surgery can be seen in Figure 3.

For the question asking what the patient thought was most important for him or her in order to feel more included in their anaesthesia the patients had five different options to choose from, seen in Table 4. Seventeen (30.9%) answered that “*Time for consultation with a physician/nurse*” was most important. Eleven (20.0%) answered “*Information about your disease/your health*”; ten (18.2%) answered “*Information about different treatment options*”; “*That the physician/nurse listens to what you have to say*” and “*To receive feedback from the physician/nurse*” respectively had four (7.3%) respondents who thought this was most important in order for them to feel more included. Eight (14.6%) had answered the question incorrectly by choosing more than one of the options and one (1.8%) had not responded to the question.
Figure 3 The figure shows the correlation between those patients who answered their preferred level of participation in the Control Preference Scale (n=53), and if they want to decide if they should be awake or asleep during the surgery.

Table 4 A list of the five different options participants could choose from in order to describe which of these options best would increase their participation.

<table>
<thead>
<tr>
<th>Information about your disease/your health</th>
<th>Information about different treatment options</th>
<th>Time for consultation with a physician/nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>That the physician/nurse listens to what you have to say</td>
<td>To receive feedback from the physician/nurse</td>
<td></td>
</tr>
</tbody>
</table>

4.2.2 Personnel

A small majority of the anaesthesia personnel, 17 of 38 (44.7%) \((agreed \ n=5; \ strongly \ agreed \ n=12)\) that patients should be allowed to participate in the decisions regarding their anaesthesia. Fifteen \((39.5\%)\) of the personnel were \(neutral\) to this statement and six \((15.8\%)\) \(disagreed\), none of the personnel did \(strongly \ disagree\). Thirty-six \((94.7\%)\), answered that, if the situation allowed, the patients should be included in the decision of whether or not they should be awake or asleep during the surgery, one nurse did not think that the patients should be included in this decision, and one physician did not answer the question.

When the personnel were asked to indicate which of five options, listed in Table 4, they thought would make patients feel more included in their care, the option “Time
for consultation with a physician/nurse”, was chosen by the majority; 22 of 38 (57.9%). The second most popular choice was “That the physician/nurse listens to what that patient has to say” ; 12 of 38 (31.6%). “Information about their disease/their health” and “To receive feedback from the physician/nurse” came joint third with respectively 2 (5.3%) respondents. No one chose the option “Information about different treatment option.” There was no difference among the answers between the two personnel groups.

4.3 Experience from the Healthcare System

4.3.1 Patients
Thirty-nine (70.9%) of the patients strongly agreed or agreed that they had been able to participate enough in the decisions regarding their anaesthesia, of these 34 strongly agreed and five agreed, two were neutral and nine (16.4%) did not feel they had been able to participate enough. Of these nine, six patients stated that they strongly disagreed to this question; the remaining three disagreed. The same six patients who responded they strongly disagreed of being able to participate enough in decisions regarding their anaesthesia also responded to another question that they had not received enough information about anaesthesia.

Twelve (21.8%) of the participants responded that they had not received enough information, of these strongly disagree (n=10) and disagree (n=2). Nine (75.0%) of these 12 had not visited the Anaesthesia clinic prior to their surgery.

A majority, 44 (80.0%), responded that they have had the possibility to ask questions to the medical personnel, three (5.5%) were neutral and one patient did not respond to the question. Seven (12.7%) had not been able to ask questions and neither of these persons had visited the Anaesthesia clinic prior to their surgery. In the cases were patients reported they had asked questions (n=41), thirty-six (87.8%) answered they had been able to understand the answers they received. Two was neutral, one disagreed and two had not taken a stand.

4.3.2 Personnel
Among the personnel 22 (57.9%) felt that they had enough opportunities to include patients in decisions regarding the patient’s own anaesthesia care, (strongly agreed n=10; agreed n = 12). Ten subjects (26.3%) were neutral; five (13.2%) disagreed to that they have had enough opportunities to include the patients in the decisions; one nurse had not taken a stand for this question. In the group of personnel that strongly agreed (n=10) to that they had enough opportunities; nine were anaesthesiologists as can be seen in Figure 4
When the personnel was asked if they had enough opportunities to provide information to the patients regarding their anaesthesia, 36 (94.7%) felt they had (strongly agreed n=24; agreed n=12). One physician disagreed and one nurse had not taken a stand. There was not a similar distribution between the physicians and the nurses. Among the 18 anaesthesiologists, 12 strongly agreed to have enough opportunities to provide the patients with information and four agreed. In the nurse group, 11 strongly agreed and eight agreed.

Twenty-nine (76.3%) of the personnel strongly agreed that they give patients the possibility to ask questions, six agree (15.8%) and three (7.9%) were neutral. There was no difference between the two profession groups.

![Figure 4](image1.png) **Figure 4** Correlation between profession groups and their belief in having enough opportunities to include the patients in decision regarding patients' anaesthesia care

Among the personnel, 29 out of 38 (76.3%) felt they had enough opportunities to take in account the patients’ own experiences of their disease/health. In this group, nine strongly agreed and 20 agreed. Five was neutral, two did not feel they had enough opportunities (disagreed n=2) and two had not taken a stand. There were some differences between the two profession groups, as can be seen in Figure 5.

![Figure 5](image2.png) **Figure 5** Correlation between profession groups and their belief in having enough opportunities to take the patients experience of their disease/health into account
4.4 Patients use of Internet

Fifty-one patients said they had not searched the internet for information about anaesthesia before their visit to the hospital; one patient did not respond to the question. The remaining three who said they had searched for information on the internet, were from the respective age group 61-70, 71-80 and 81-90.

Among the personnel thirteen (34.2%) answered that they believed that the majority of the patients at the hospital researched the internet for information about anaesthesia prior their visit to the hospital; of these 13, 10 (76.9%) were nurses shown in Figure 6. Twenty-five (65.3%) answered they did not believe that the majority of the patients search the internet. Of the 13 personnel that answered positively, six (46.2%) were in the age-group 21-30 years, visible in Figure 7.

4.5 Answers to the Open-Ended Questions

4.5.1 Patients

A minority of the patients (n=13) chose to answer the open-ended questions: Is there some part of your care you think is especially important to participate in? The majority of those who answered this question responded with an answer connected to information (n=9). For example, one patient answered: “To receive information is most important, in that way I can form my own opinion”; another answer was “Important to receive information and to ask questions”.

When asked if there was something they would like to add connected to their participation in their anaesthesia, two participants answered. One said “I have received poor information prior to my surgery. The anaesthesiologist should have called me before the surgery but did not” the other participant answered “I should
have been able to ask about general or local anaesthesia”. Neither of these two patients had visited the Anaesthesia clinic prior to their surgery.

4.5.2 Personnel
On the open-ended question: Is there some part in the care you think is especially important for the patient to participate in? exactly half (n=19) of the personnel group chose to answer. There was diversity among the answers on this question. Several answers were connected to information; for example, one nurse answered: “It is important that they receive the right information in order for them to feel/experience participation”. Other answers were connected to the visit at the Anaesthesia clinic prior to the surgery; for example, one physician answered “That they are given time at the pre-anaesthetic consultation”.

The open-ended question which more specifically asked about the patients’ participation in anaesthesia: Is there something you would like to add regarding the patients participation connected to anaesthesia? had a total of 12 respondents. The answers were mostly connected to information about anaesthesia and its connection to patients’ participation. One nurse answered: “It is important that the patients are well informed and receive information about different anaesthesia methods, and pros- and cons with regards to the procedure”. A physician answered: “It is difficult for the patients to hand over the control. I believe good information and calmness/comfort is important for the patients’ experience”
5 Discussion

Considering that the new patient act adopted by Sweden in 2015 advocates for patient participation this is an area which is timely and important to investigate. However, it is not clear how the healthcare system should work in order to achieve greater patient participation. In addition, there is a lack of a clear definition for the term patient participation [30], adding to the complexity of patient participation as a concept and making it harder for the healthcare service as a whole to embrace patient participation. Furthermore, there exists gaps between what is considered an ideal participation and actual patient participation [18]. Due to this, it is imperative to collect information from patients and personnel with regard to how they experience and what they expect from patient participation in order to close the gap between ideal participation and actual participation.

The aim of this thesis was to collect information from patients and personnel concerning their experiences of patients’ participation in the healthcare; this information would in turn help the Anaesthesiology and Intensive Care Unit at Danderyd Hospital to continue their work to include the patients more in their care. In order to reach the aim of this thesis three research questions were formulated on the subject of patients’ participation in the healthcare. This discussion is structured around the theme of the three research questions.

5.1 Discussion of method

In order to gather data from many participants during a limited amount of time a quantitative method was chosen. A cross-sectional survey allows for much data to be collected and the possibility to generalize the findings for the specific group. Moreover, two open-ended questions were added to the survey in order to enable the participants to contribute with information they thought was important but which the structured questions had missed. Both patients and personnel were surveyed in order to gain a more comprehensive understanding of their respective areas. The questionnaire was kept short in order to avoid non-responses since longer surveys could discourage people from participating in the study. Therefore, only 15 questions were included in the survey. In order to minimize misunderstandings among the participants, they each received oral and written information from the researcher about the survey prior to their participation. All patients that participated in this investigation had the possibility to ask questions when they filled out the questionnaire. Due to the working environment of the personnel it was not possible for them to answer the survey during a time when the researcher was present.

Questions from the National Patient Survey were included in this study in order to increase the validity of the survey. The National Patient Survey uses a five-point Likert scale which enables the respondents to grade their answers to the different questions between Strongly agree to Strongly disagree. Normally a five-point Likert scale is used in order to let respondents agree to a statement; however, the National Patient Survey uses questions instead of statements. The questions which were created by the research from the literature were formulated in the same way as the
National Patient Survey questions in order to make it easier for the participants to answer.

In order to assess the patients preferred role in the decisions connected to anaesthesia the Control Preference Scale was used. This is a method which has been used in different areas within the healthcare setting for a long period of time and has been found to be a reliable measurement for patients’ preferred participation in decisions [52]. Only two out of 55 participants failed to answer this specific question which indicates that the majority of the patients understood what they were being asked. To further assess the patients preferred level of participation in decisions concerning anaesthesia, and to assess the reliability among the answers, the patients were asked if they would like to be part of the decision about if they should be awake or asleep during surgery in cases where this would be possible. Compared to the Control Preference Scale this question provides a concrete example for the patients which is easier to grasp and thus understand. From the results of these two questions it was possible to see that there were stable answers from the patients and thus a high reliability.

A problem when dealing with research concerning patient participation is that different methods could yield different results. A literature review performed for this thesis has shown that all included studies where questionnaires had been used resulted in higher satisfaction ratings compared to studies which had been using some kind of recording instrument which presented more ambiguous results [30]. This is important to bear in mind when the present results are evaluated; in this case, this might mean that the results could have been less positive if a more qualitative method would have been used.

Neither parametric tests nor non-parametric analysis could be performed; first, because the data was too skewed and second because there were too few participants. Due to this, it is not possible to know if the results are significant or not. However, the overall non-responses within the survey where low indicating that the participants understood the questions in the questionnaire and felt able to respond; therefore, the same questions could be used again with a higher number of participants in order to be able to perform statistical analyses. It would not be a problem to gather more patient participants; gathering more personnel might be considerably more difficult as there is a limit to how many individuals work at any one specific care unit. One way to overcome this problem would be to include personnel from similar care unit at different hospitals.

Since there is a lack of a clear definition for the concept of patient participation [30], conducting research in this area can be challenging. This thesis investigated patients’ and personnel’s views on patient participation without defining patient participation. Instead subjects were asked to answer from their own experience. It is important to remember this when the results from this thesis are assessed, since they are showing the perspective from each individual participant’s own experience and preferences. If patient participation as a concept beforehand would have been explained to all participants the answers could have been analysed with the knowledge that each participant had the same understanding of patient
participation. Future studies could formulate a definition of patient participation and present it to the participants [38] before they are asked to answer the survey.

5.2 Preferred Level of Participation

This part of the discussion focuses on the results collected to answer the first research question: *Is it possible to identify characteristics within patient groups which connect to their preferred level of participation in their own healthcare decisions?*

The results from this study show that the majority of the patients (45.5%) wanted to be passive in the decisions. This is an interesting result considering that the new patient act aims to promote the participation of patients in their care but the majority of the patients included in this thesis wanted to be passive in their care and thus not be the person making the decisions. A small majority of the patients (14 of 25) who ranked themselves as passive, did in addition not want to be included in the decision about if they should be awake or asleep during the surgery. This shows that they in a concrete situation preferred to leave the decision to the medical personnel and thus further indicates their desire to be passive. Patient participation is often recognized as being positive for the individual patient; however, it is also important to recognize that not all patients want to participate [17] and that if the patient wishes to be passive his or her wishes should be respected [18]. In addition there exists research which indicates that patients that do not want to participate, but who nevertheless are asked to choose, experience distress and anxiety [51]. With this in mind, it is important to understand that patient participation can lead to uncomfortable experiences for a certain type of patients and it might thus not be favourable to make them participate.

Even though the majority of the patients in this thesis preferred to be passive, 21.8% wanted to be active in the decisions. All of these patients also wanted to be included in decision about if they should be awake or asleep during surgery, indicating stable answers from the participants and thus a high reliability in the questions. These patients should be allowed to participate in their care seeing that previous research has shown that patient participation could lead to better health outcomes and increased patient safety [15, 25-27]. In addition, the 29.1% of the patients that preferred the collaborative role where the responsibility is shared between the patient and the clinician should also be allowed to participate and share the responsibility in the decisions due to the same reasons mentioned above.

When the personnel were asked if they thought patients should be allowed to participate in the decision to decide if patients should be awake or asleep during the surgery, the majority (94.7%) answered yes. This indicates that the personnel want to include patients in the decisions. However, when the personnel were asked whether they thought the patients should be allowed to participate in decisions regarding anaesthesia, only a small majority (44.7%) answered that they agreed the patients should be allowed to participate. Thirty-nine point five percent were neutral to this statement and the rest did not think the patients should be allowed to participate in the decisions. Why the great majority of the personnel wanted the patients to be included in the decision if they should be awake or asleep but not the same majority thought that patients should be allowed to participate in decisions
regarding anaesthesia is not clear from these results. One reason for the difference between the answers of these two different questions could be because the personnel makes a number of decisions connected to the anaesthesia and that they believe the patients should be included in some of them, such as the one connected to if they should be awake or asleep, but not others. Future studies could investigate this by using a qualitative method in order to identify why personnel would like patients to participate in some decisions but not others, and also to elicit which types of decision fall into this category. Further investigation of personnel preferences regarding patient participation is important because the personnel’s attitudes could have an effect on patients’ preferences for involvement. In a study investigating patients’ willingness to participate in areas concerning safety, and how the personnel could encourage them, it was found that the personnel may be able to increase patient involvement by encouraging them [53].

5.2.1 Characteristics for Preferred Level of Participation

Much of the previous research on the willingness of patients to participate has found that older persons are less likely to desire involvement in their care [15, 27, 54]. In the results from this study it was not possible to see any correlation between age and patients desired level of participation; however, this could have been different if there were more participants in the ages 18-50. Nevertheless, one study conducted in Sweden found no correlation between age and patients’ willingness to participate [52]. Similar to this study, they had participants with a high age, ranging from 76-86 years and the majority of the participants wanted to be passive in their care. The authors concluded that participation was not possible to predict among elderly patients, and that the preferred level of participation is connected more to the individual person than to age.

The present results showed that 62.5% of the women would prefer to be passive in their care and for the men this number was 38.5%. These results contradict much of the previous research where it was often found that women are more likely to desire involvement in their care compared to men [15, 27, 54]. Seeing that 70.9% of the participating patients where men, these results are not representative for the population and might be the reason why the current findings do not correspond with previous research.

Many researchers draw the conclusion that depending on the individual there is a willingness to participate at different levels [15, 18, 25, 31], which supports the idea that the care should be adapted for each individual person instead of finding general characteristics for patients preferred level of participation. Since it was not possible to see trends related to age in the results from this thesis, and that the results indicating that women preferred a more passive role compared to men which contradicts much of the previous research, this could be of support to the research which concludes that the desire to participate depends on the individual rather than other personal attributes. Furthermore, one study argues that giving patients the opportunity to participate and providing them with information is not enough in order to enhance participation; the patients need to be seen as individuals and their own knowledge should be respected [55].
5.3 Experience from the Healthcare System

In order to continue the work of better including patients in their care it is important to understand what stakeholders within the current healthcare system experience. The second research question in this thesis: How is patient participation within the area of anaesthesia experienced by two different groups: patients and personnel? was designed with the aim to better understand what the patients’ and personnel's experiences are from the healthcare provided at present. In this section the patients' experiences are presented first; and the personnel's experiences second.

The great majority of patients in this study agreed that they had been able to participate enough in the decisions regarding their anaesthesia. Only nine of the 55 participants felt they had not been able to participate enough. Thus, these results indicate that the majority of the patients were satisfied with their level of participation in their care. However, some characteristics were found among the patients that did not feel they had been able to participate enough; these are discussed in section 5.4.

In order to include the patient and let them participate in decisions connected to anaesthesia it is important to understand whether or not the personnel have enough opportunities to include the patients in the care. The results from this survey showed that 57.9% of the personnel felt they had enough opportunities to include the patients in the decisions, which is a majority. However, in the group of personnel that felt they had enough opportunities ten strongly agreed and nine out of these ten were physicians. This indicates that the physicians feel they have better opportunities to include patients in decisions compared to the nurses. In order to create a better working environment for the nurses and increase the possibility for allowing patients to participate; this is an area which should be further investigated.

5.4 Factors Connected to Patients’ Participation

One way of continuing the work of increasing the patients’ participation in their care is to better understand what different factors within the healthcare are connected to the patients’ participation. The third research question in this thesis: Are there factors identifiable within the care experience which either facilitate or hinder the participation of patients in their care? was constructed in order to identify factors in the healthcare which either facilitated or hindered the patients’ participation. The results indicate that some areas such as: information; possibility to ask questions; and communication between patient and personnel could be connected to the patients’ participation. These three areas are discussed in the following sub-sections.

5.4.1 Information

From previous research it is known that information most likely is an important factor connected to patients’ participation in their care. For example, when patients have been given information they are more likely to want to participate in decisions [25] and it is likely that patients need suitable information in order to participate [38]; this highlights the importance of providing patients with information. The results from the open-ended questions in this study indicate that information is an
area where patients feel they should participate, particularly seeing that the majority of the answers to the open-ended questions concerned information. From this it can be assumed that information is not only viewed as important from a scientific perspective, but that it also is perceived as an important aspect for many of the patients.

Additional results from this study indicate that the patients' experience of their participation is connected to information. Out of the nine participants who felt they had not been able to participate enough in the decisions regarding anaesthesia, six additionally felt they had not received enough information about anaesthesia. For this specific study, this suggests that not receiving enough information is connected to experienced participation among the patients; thus patients' participation could be hindered by not receiving enough information. Due to the small number of participants in this study it is not possible to test for significance of these results; however, the link between how lack of information and the experience of an insufficient participation are connected is an area in need of further investigation.

A study conducted in Helsinki investigating the content of the verbal information given at a preoperative clinic found that 25.0% of the patients felt they had not received enough information about the benefits of anaesthesia [42]. The result from this present study shows similarities, seeing that 12 of the 55 patients (21.8%) felt they had not received enough information about their anaesthesia. The authors of the study in Helsinki argue that one reason for the high number of patients feeling uninformed could be due to that physicians overestimate how informed the patients actually are and believe it is clear to the patients what the benefits of anaesthesia are. This might be the reason in the present case as well; however, of the 12 patients that felt they had not received enough information, nine had not visited the Anaesthesia clinic prior to their surgery. Due to this, it is more likely that the reason why the patients felt uninformed is because they had not received information from the hospital, rather than that the medical personnel have overestimated the patients' prior knowledge of anaesthesia.

There are other results from the present study which indicate that the Anaesthesia clinic is important in order to provide patients with information. When specifically asked about their participation in anaesthesia, the two patients who chose to answer both responded with negative answers, saying they had received too little information, and neither of those two patients had visited the Anaesthesia clinic prior to their surgery. One of them had not been able to speak with an anaesthesiologist prior to surgery and that the other had not been able to ask questions about general or local anaesthesia; if they had visited the Anaesthesia clinic their responses would probably be different.

Furthermore, when the personnel were asked if they believed themselves to have enough opportunities to provide the patients with information regarding their anaesthesia, 36 of 38 believed they had. These results indicate that the personnel have sufficient resources to inform the patients; and that the reason why some of the patients felt they had received too little information about anaesthesia is
probably connected to the fact that they have not visited the Anaesthesia clinic prior to their surgery and thus not been in contact with any medical personnel.

When the patients were asked to choose one of five options for what they believed would increase their participation in their care the second and third most chosen options were information about their disease/health and information about different treatment options. This is thus another example indicating that information is an area within the healthcare that patients value as important in order to participate more.

Conversely to what the patients had chosen it was only a minority of the personnel, two in total, that had chosen the options related to information. From these results it is not possible to understand why patients are more likely to say that information would increase their participation compared to the personnel. Nevertheless, many of the personnel responded to the open-ended questions with answers connected to information. One example being the nurse who answered that information was important in order to increase patient participation, this answer corresponds well with much of the research which states that information and participation are connected to each other.

Information to the patients regarding anaesthesia is important seeing that research has shown that information can have an effect on patients. For example, a pre-operative education could reduce the anxiety that patients might experience and thus increase the chances of a more positive outcome; such as lower pain levels [41]. This is relevant for the results in this case considering that patients who have not visited the Anaesthesia clinic prior to their surgery are more likely to feel that they have not received enough information. In addition, more specific for the anaesthesia setting, it has been shown that patients desire to receive information about pain control; surgery; anaesthesia options; common complications; and medication [41]. It is likely that patients need individualised information in order to be able to participate [38]. Thus, knowing what kind of information patients’ desire and understanding that information has an effect on patients can facilitate the work of including patients in their care and thus increasing their participation in decisions. Future studies could for example, investigating how patients prefer to receive information and what kind of information they would like to receive.

5.4.2 Asking Questions
One way for patients to receive information is by asking questions. It has previously been discussed in other research that asking questions is connected to patient participation. One example is a study which investigated how the patients communication style shaped the physicians dialogue; they found results which indicated that the patients’ participation was associated with an increase of information from the physician, as a response to the patients’ questions [28]. They further suggested that the patients’ participation either forced the physicians to answer the patients’ questions more thoroughly or that the physicians’ responsiveness to the participating patients encouraged them to ask more questions. The results from this thesis showed that 80.0% of the patients felt they have had the possibility to ask questions. Of the 55 patients, 41 answered that they
had asked questions and 36 of them had understood the answer they received. This points to that the majority of the patients have the opportunity to ask questions and that they receive answers which they understand; these are positive results considering that being able to ask questions could be connected to patients' participation. The results from the personnel support the fact that patients are given the opportunity to ask questions since 92.1% of the personnel responded that they give patients the opportunity to ask questions.

Only seven (12.7%) of the patients answered they had not felt they had the possibility to ask questions and none of them had visited the Anaesthesia clinic prior to their surgery. This indicated that the patients who do not visit the Anaesthesia clinic prior to their surgery are more likely to feel that they have not had the possibility to ask question and again stresses the importance of the Anaesthesia clinic as a way of informing patients about anaesthesia prior to surgery. Seeing that existing literature points to a relation between patients’ participation and asking questions; one facilitator for participation could be to allow all patients to meet with medical personnel in order to provide them with the possibility to ask questions.

5.4.3 Communication between Personnel and Patient
Research has previously shown the patients experience participation if the personnel listen and respect the patients knowledge about their body and situation [55]. Due to this it is important that the personnel feel they have enough opportunities to take the patients experience about their disease/health into account. Results from this study indicate that the majority (76.3%) of the personnel have enough opportunities to take the patients' own experiences into account. Being able to listen to and recognise the patients’ own knowledge of their health status is important in order to include the patients in the decisions and thus share the decisions; one way of doing this is by shared decision making which is discussed more at length in section 5.5.2. Furthermore, the second most chosen option for what the personnel believed to be important in order to increase the patients participation was that the physician or nurse should listen to what the patient had to say. Research in the area of patient participation describes that being listened to is described as patient participation by the patients [44] and the results from this study indicates that the personnel acknowledge this and know that acknowledging what patients think is important for them to participate more.

Although the majority of the personnel had enough opportunities to take the patients' own experience about their disease/health into account, the results indicate that there was a difference between the nurses and physicians in the group of the personnel that strongly agreed they had enough resources; of these nine, seven were physicians. This small trend that physicians to a greater extent compared to the nurses feel they have enough opportunities to take the patients' own experience into account is parallel to the results concerning the difference between the two groups of personnel's feelings towards their opportunities to include the patients in the decisions, discussed in section 5.3. Once again it is not possible to fully understand the difference between the physicians and nurses only from the results presented in this thesis; however, this should be an area of future investigation.
From the results it is possible, however, to understand that *time for consultation with a physician or a nurse* is important for the patients in order for them to be able to participate more in their care; of the five options the patients could choose from (in order to decide what they thought was most important in order to be able to participate more), this was the option with most responses. Consistent with what the patients answered, the majority of the personnel (57.9%) also thought that time for consultation with a physician or a nurse was most important in order to include the patients more in their care. A visit at the Anaesthesia clinic prior the surgery is one way to let patients spend time with a clinician and could be a way to enhance and facilitate patients feeling of participation.

### 5.5 Information Technology

The results from this thesis can help to increase the different stakeholders' understanding of patients' participation in their care; in addition, the results can serve as a foundation for continued discussions on how patients should or can be included in their care. Considering that patient participation is promoted in the new patient act, innovations and development of technology and the healthcare system should aim to support patients' participation. As mentioned in the introduction it is the patients' needs that creates the foundation for innovation [13] and development of technology from the patients perspective could lead to better health outcomes [5].

The first part of this section discusses the results on patients' use of internet in order to search for information prior to their visit at the hospital and how this could have an effect on the provided care. As mentioned in the introduction, it is generally assumed that people are able to become more informed by the use of internet and this could have an impact on the healthcare system. The second part of this section discusses shared decision making and how that can be used by the help of different IT-systems as one way of increasing patients' participation.

#### 5.5.1 Patients use of the Internet

It is generally assumed that patients increasingly use the internet in order to search for health information [10, 56]. However, the results from this thesis indicate that the great majority of the present patients (94.4%) did not research the internet for information about anaesthesia before their visit to the hospital. Considering that only three of the 55 participants answered that they had used the internet before their visit to search for information about anaesthesia makes it difficult to identify characteristics or make assumptions among patients who search for information on the internet. Nevertheless, it is interesting that these three patients were found in the age group 61-90. In a Swiss study investigating how internet informed patients affected communication with clinicians it was found that searching the internet before a visit to the hospital was not yet the norm [56]; which could be the case in this study as well.

The results regarding whether or not the personnel thought that the majority of patients searched the internet for information is more in line with what one might imagine. Among the personnel, 34.2% believed that the majority of the patients search the internet for information before their visit to the hospital. How the personnel answered this questions was very different between the nurses and physicians, 50.0% of the nurses thought patients searched the internet for
information which was a higher number compared to the physicians. However, the results also showed that in the age group 20-30, where the majority of personnel were nurses, six out of seven believe that the majority of the patients researched the internet for information. Considering that the age group 20-30 was the only age group where the majority believed that patients search the internet for information it could indicate that younger personnel, compared to older personnel, have less knowledge concerning patients internet habits before they visit the hospital, rather than that the nurses have less knowledge compared to the physicians. From this study, it is not possible to understand why there are such differences between the age groups. For example, it could either be because this age group has less experience compared to the older age groups, or it could be because they themselves would search the internet and so these persons assumed that patients do the same. Nevertheless, 65.3% of the personnel assumed that the majority of the patients do not search the internet before their visit indicating that they have a good understanding of how informed their patients are before their visit.

How the general public uses the internet and what health information they gather is an area which needs further investigation as this is a potential means of communicating important information to the general public and involving patients in their care. It is also important because if there are assumptions that the general public have access to the same information as clinicians it needs to be confirmed or denied [57]. Furthermore, it is important to understand how the communication between patients and medical personnel could be affected by better informed patients. A study in the United Kingdom found that internet informed patients want the physician to acknowledge that they have searched for information; however, in most cases they still follow the physicians advice even if it contradicts the information from the internet, as long as it is thoroughly explained by the physician [58].

5.5.2 Shared Decision Making
Connected to how the general public uses the internet is the area of shared decision making; in order to practice shared decision making it is important that the patients are informed [33]. Practicing shared decision making is also one way of increasing the patients’ participation in their care. Shared decision making can be performed with help from patient decision aids which are aids designed to help people make informed decisions regarding their treatment [59]. Today, there exist different IT-systems which enables clinicians and patients to communicate with each other and could be a way to increase the patients involvement in their care [26]; which is another example for why there is a need of further investigations in the area of communication between patients and personnel. Using these kinds of IT-systems for shared decision making could be a way of increasing the amount of information available for the patients. Seeing that patients are more likely to participate if they receive information [25, 38] creating shared decision making systems in order to better inform the patients could be a way of increasing patients participation in their care.

The Mayo clinic in USA is working with shared decision making where it is mainly used for patients with chronic diseases [60]. They have created user-centred
information both for interactive use on the internet and information on paper [61]. However, there exists other more easily adaptable ways to include the patients with help from IT-systems. As mentioned in the introduction, the patient could be invited to look at electronic health records on the screen together with the clinician; this could improve shared decision making, patient participation and communication between patients and personnel [35]. Compared to creating or implementing a shared decisions making system this is easier to test seeing that the technology already is available at all Swedish hospitals.

### 5.6 Implications for the Healthcare

Many of the results presented in this thesis point towards the importance of assessing and understanding each patient individually; seeing that the results from this study and previous studies indicates that the patient preferred level of participation is connected to the individual rather than other characteristics. Understanding the knowledge and desires the individual person possesses, and being able to provide care resulting from that knowledge and desires, are valued as important aspects in person-centred care; providing person-centred care can thus be a way of increasing the patients' participation in decisions within the healthcare environment.

For example, patients should be provided with the information most suited to them, and medical personnel should listen to what experiences the patients’ have of their own health in order to create a partnership with the patient. These examples are thought to be facilitators for an increased patient participation but also important in person-centred care [62]. Furthermore, respecting the patient as an individual is also highlighted as important in the new patient act; thus it seems as if increased patient participation and promotion of patients' self-determination can be achieved with similar methods. However, even though the new patient act aims to increase patients participation it is important to understand that not all patients would choose to participate in decisions and their wishes should be respected.

### 5.7 Implications for Engineering

The results from this study can help to better engineer future healthcare services and technologies from both the patient and personnel perspective. For example, as patients’ participation is probably most strongly dependent on the individual, services and technologies which aim to increase participation should be designed to support the individuals’ preferences and needs. In addition, as these results also indicate that there exists a small difference between nurses’ and physicians’ feelings towards the possibilities to include patients in their care, and to take patients’ own experiences into account, new technologies and information systems should be designed with an aim to decrease these differences. Thus, before new technology and information systems are created, nurses and physicians should be consulted on how they believe new solutions could be designed in order to support their daily work.

It is also important not to forget that the results from this study show there is a high satisfaction among the personnel and the patients, thus when new technologies and systems are designed it is important that it supports the current situation and dose
not disrupt it. Surveying personnel and patients prior and after the implementation of new services or technologies could be a useful method in order to assess if the changes had the desired effect.

Lastly, information is an important part of the patient's ability to participate and IT-systems could be an effective way of informing patients. Creating systems which would allow patients the possibility to gain information by themselves could be one way of better informing the patients.

5.8 Future Investigations
The results from this study contribute with information on patient participation in an anaesthetic healthcare setting. However, the results presented in this thesis show that the majority of the patients overall are satisfied with their care, which is positive for the hospital; but makes it hard to understand where improvements could be made in order to better satisfy the patients in the area of patient participation. Other studies have previously discussed the problem of improving the care when there is an overall high level of satisfaction among patients [38]. Thus, it is known that it can be problematic to create solutions for the healthcare only from the patients’ perspective. Surveying personnel could be a way to overcome this challenge in the hope that they can identify areas which they think is important to improve. Other ways to overcome this problem could be by using qualitative approaches in order to better understand why patients overall are satisfied. In addition, the results from this study indicate that it is possible to gain better knowledge of patients’ and personnel’s attitudes and experiences of patient participation by the use of a survey. It allows for a relatively high number of participants to answer in a short period of time. Even though it is not possible to identify underlying reasons for why participants answer as they do with surveys, surveys could be used in order to identify areas which are in need of further investigations.

The area of patient participation needs further investigation; from these results four different areas have been identified as possible topics for future studies. First, only three out of the 55 patients who participated in this study had searched the internet for information prior to their visit at the hospital. Today, it is generally assumed that patients use the internet to search for information but the results from this study indicate the opposite; this is important to investigate in order to better understand if the general assumptions could have an effect on how much information personnel provide the patients. Second, the majority of the patients preferred a passive role in their decision making which is interesting since the new patient act aims to involve the patients more in their care. Further studies should aim at investigating if it would be preferable to adapt the care to these passive patients; or if it would be better to find ways of persuading these patients to desire a more active role. Third, results from this study indicate that patients who have not visited the Anaesthetic clinic prior to their surgery feel less informed than those who did visit, and in addition feel they have not been able to participate enough. Future studies should investigate if there are connections between these factors; but also investigate if information could be provided to patients by the use of IT-systems and thus be a way of better informing patients who do not visit the Anaesthetic
clinic prior to their surgery, thereby increasing their participation. Fourth, there were small trends which indicated that the physicians felt they had better opportunities to include the patients in decisions and to take the patients experiences into account compared to the nurses. In order to create a better working environment for the nurses, further studies should try to understand why physicians felt they had better opportunities compared to the nurses.
References


Appendix A
Patientenkät

Enkäten består av 15 frågor och det tar cirka 5 minuter att svara. Frågorna syftar till att ta del av dina åsikter och erfarenheter om din delaktighet i vården kring din bedövning/narkos.

Om dig

1. Kön: □ Man □ Kvinna □ Vill ej uppgä

2. Ålder: □ 18-30 år □ 31-40 år □ 41-50 år □ 51-60 år □ 61-70 år □ 71-80 år □ 81-90 år □ över 90 år □ Vill ej uppgä

3. Vilken typ av operation ska du genomgå?
□ Ortopedisk □ Kirurgisk □ Urologisk □ Vet ej

4. Har du innan din operation idag haft kontakt med en narkosläkare eller narkosköterska?
□ Nej □ Ja, via telefon □ Ja, på besök hos Anestesimottagningen

5. Har du inför ditt besök idag sökt information om bedövning/narkos på internet?
□ Ja □ Nej

Delaktighet

6. Har du känt dig tillräckligt delaktig i besluten beträffande din bedövning/narkos?
Ja, helt och hållet □ □ □ □ Nej, inte alls □ Har ej tagit ställning

7. Vill du i de situationer där det är möjligt i samråd med läkaren/sjuksköterskan fatta beslutet om du ska vara sövd eller vaken under operationen?
□ Ja
□ Nej, jag vill att läkaren/sjuksköterskan ska fatta det beslutet
□ Har inte tagit ställning/är inte aktuellt

8. Vill du att dina anhöriga ska få vara delaktiga i besluten kring din bedövning/narkos?
Ja, helt och hållet □ □ □ □ Nej, inte alls □ Har ej tagit ställning

9. Har du fått tillräckligt med information om din bedövning/narkos?
Ja, helt och hållet □ □ □ □ Nej, inte alls □ Har ej tagit ställning
10. Har du haft möjligheten att ställa frågor till en läkare/sjuksköterska angående din bedövning/narkos?
   Ja, helt och hållet ○—○—○—○ Nej, inte alls □ Har ej tagit ställning

11. Om du har ställt frågor, fick du svar som du förstod?
   Ja, helt och hållet ○—○—○—○ Nej, inte alls □ Jag ställde ej frågor

12. Anta att du har fått information om din sjukdom/ditt hälsostillstånd av en läkare/sjuksköterska, vilket av dessa påståenden passar då bäst in på din önskade nivå av delaktighet i beslut kring bedövning/narkos?
   a) Jag föredrar att själv fatta det avgörande beslutet i min bedövning/narkos
   b) Jag föredrar att fatta det avgörande beslutet i min bedövning/narkos efter att jag grundligt har övervägt min läkares/sjuksköterskas åsikter
   c) Jag föredrar att min läkare/sjuksköterska tillsammans med mig delar på ansvaret för att fatta beslutet om vilken bedövning/narkos som är bäst
   d) Jag föredrar att min läkare/sjuksköterska fattar det avgörande beslutet i min bedövning/narkos men att läkaren/sjuksköterskan grundligt har övervägt mina synpunkter och önskemål
   e) Jag föredrar att min läkare/sjuksköterska fattar alla beslut i min bedövning/narkos

13. Markera det alternativ som du tycker är viktigast för att du ska kunna känna dig mer delaktig i din bedövning/narkos:
   □ Information om din sjukdom/ditt hälsostillstånd
   □ Information om olika behandlingsalternativ
   □ Tid för samtal med läkaren/sjuksköterskan
   □ Att läkaren/sjuksköterskan lyssnar på det du har att berätta
   □ Att få återkoppling från läkaren/sjuksköterskan

14. Finns det någon del i din vård/behandling som du tycker att det är extra viktigt att vara delaktiv i?

15. Är det något du vill tillägga om din delaktighet i din bedövning/narkos?

   Tack för din medverkan!
Personalenkät

Enkäten består av 15 frågor och det tar cirka 5 minuter att svara. Frågorna syftar till att ta del av dina åsikter och erfarenheter om patienter och anhörigas delaktighet i vården kopplad till anestesin.

Om dig

1. Vilken yrkeskategori tillhör du? □ Läkare □ Sjuksköterska
   □ Annat: __________________________

2. Ålder: □ 20-30 år □ 31-40 år □ 41-50 år □ 51-60 år □ 61-65 år
   □ över 65 år □ Vill ej uppge

3. Hur många år har du arbetat inom vården: ________________________

Delaktighet

4. Tror du att majoriteten av patienterna söker information om bedövning/narkos på internet innan besök på sjukhuset? □ Ja □ Nej

5. Tycker du att patienter ska få vara delaktiga i beslut beträffande bedövning/narkos?
   Ja, helt och hållet ○—○—○—○ Nej, inte alls □ Har ej tagit ställning

6. Känner du att du har tillräckliga förutsättningar för att låta patienten delta i beslut beträffande bedövning/narkos?
   Ja, helt och hållet ○—○—○—○ Nej, inte alls □ Har ej tagit ställning

7. Känner du att du har tillräckliga förutsättningar för att ta hänsyn till patienteras egna erfarenheter av sin sjukdom/sitt hälsotillstånd?
   Ja, helt och hållet ○—○—○—○ Nej, inte alls □ Har ej tagit ställning

8. Tycker du i de situationer där det är möjligt att patienten ska få vara med och fatta beslutet om de ska vara sövda eller vakna under operationen?
   □ Ja
   □ Nej
   □ Har ej tagit ställning
9. Tycker du att anhöriga ska få vara delaktiga i besluten kring en patients bedövning/narkos?
   Ja, helt och hållet ☐☐☐☐☐ Nej, inte alls ☐☐☐☐☐ ☐ Har ej tagit ställning

10. Känner du att du har tillräckliga förutsättningar för att lämna ut information till patienten om dennes bedövning/narkos?
    Ja, helt och hållet ☐☐☐☐☐ Nej, inte alls ☐☐☐☐☐ ☐ Har ej tagit ställning

11. Ger du patienten möjlighet att ställa frågor?
    Ja, helt och hållet ☐☐☐☐☐ Nej, inte alls ☐☐☐☐☐ ☐ Har ej tagit ställning

12. Om patienten ställer frågor till dig, upplever du att de i majoriteten av fallen förstår dina svar?
    Ja, helt och hållet ☐☐☐☐☐ Nej, inte alls ☐☐☐☐☐ ☐ Har ej tagit ställning

13. Markera det alternativ som du tror är viktigast för att patienten ska känna sig mer delaktig i sin bedövning/narkos **Du får bara kryssa i ett av alternativen**
    □ Information om sin sjukdom/sitt hälsotillstånd
    □ Information om olika behandlingsalternativ
    □ Tid för samtal med läkaren/sjuksköterskan
    □ Att läkaren/sjuksköterskan lyssnar på det patienten har att berätta
    □ Att patienten får återkoppling från läkaren/sjuksköterskan

14. Finns det någon del i vården/behandlingen som du tycker det är extra viktigt att patienten är delaktig i?

15. Är det något du vill tillägga om patienters delaktighet i vården kopplad till anestesin?

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_Tack för din medverkan!_