

**Master thesis**

# The perspective of older patients with polypharmacy on their role in in-hospital medication safety



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## Abstract

**Background:** Prescribed medication could (unintendedly) play an important role in causing medication-related adverse effects amongst patients. Especially older patients with polypharmacy are at risk for (potentially preventable) medication-related hospital admissions. Previous research has indicated that patient participation could fulfil a key role in reducing medication errors. However, it is yet unclear how older patients perceive their own role in medication safety. **Objective:** To explore the view of older patients with polypharmacy on their role in in-hospital medication safety. **Setting:** Jeroen Bosch Hospital, wards of general surgery, urology, internal medicine and cardiology. **Methods:** Ten semi-structured interviews have been conducted with older patients with polypharmacy. The interviews took place after discharge at the patients' homes. Interview topics concerned the patient's needs, wishes and previous experiences in terms of information, involvement in (decisions on) medication and their current and preferred role in in-hospital medication safety. **Results:** Findings of this study show that patients found clear, transparent communication and information important, especially when it concerned medication changes. The patient's role in medication safety could be divided into three categories: active, passive and intermediate. Which role a patient fulfilled could potentially be dependent on several personal factors, including educational level, gender, health status, length of- and experience with disease(s). In addition, healthcare professionals could contribute to patient participation by listening to-, encouraging and involving patients in medication safety. **Conclusion:** Depending on their own needs, wishes and experiences, patients can freely choose their preferred role in in-hospital medication safety. However, it is crucial that patients are provided with important information about their medication to enable them to participate if desired.

**Keywords:** medication safety, older patients, polypharmacy, patient-centered care, patient participation, patient role

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## 1. Introduction

For many people, the hospital offers a safe haven in times of illness. A place surrounded by healthcare professionals, providing the most suitable treatment and medication for each unique individual. However, sometimes this prescribed medication could unintendedly play an important role in patient harm when causing medication-related adverse effects among patients. In 2014, 16.838 medication related incidents in Dutch hospitals were reported to the Central Medication-incidents Registration (CMR) <sup>[1]</sup>. It appeared that 2.4% of all admissions and 5.6% of the emergency admissions in Dutch hospitals were related to medication incidents <sup>[2]</sup>. Almost half of these medication-related hospital admissions (46.5%) were classified as potentially preventable <sup>[2, 3]</sup>. The consequences of medication errors not only influence the patient's health, but also affect other factors within the health care setting. Due to adverse effects of medication, the average length of stay within the hospital is extended with 6.2 days. This extra time is associated with additional costs of €2507 per person <sup>[4]</sup>. With 19.000 potentially preventable medication-related hospital admissions a year, estimated at a cost of 85 million euro per year, this forms a major burden at the expense of society <sup>[2]</sup>.

The group that seems to be affected most by medication-related incidents in the health care sector consists of older patients (65 years or older) <sup>[5, 6]</sup>. About two third of Dutch elderly suffer from two or more chronic diseases and use multiple medications for this multi-morbidity <sup>[7]</sup>. The daily use of five or more different medications is called polypharmacy and currently comprises 44.3% of the Dutch elderly <sup>[8]</sup>. It appears that the number of patients with polypharmacy is positively associated with age (see Figure 1) <sup>[9]</sup>. In addition, polypharmacy is found to be an important risk factor for potentially preventable medication-related hospital admissions amongst elderly. The frequency of medication-related hospital admissions amongst patients of 65+ is twice as high compared to patients younger than 65 <sup>[2]</sup>. Especially the patient group of 75 years and older is vulnerable for medication incidents with 23% having a daily use of seven or more different medications.

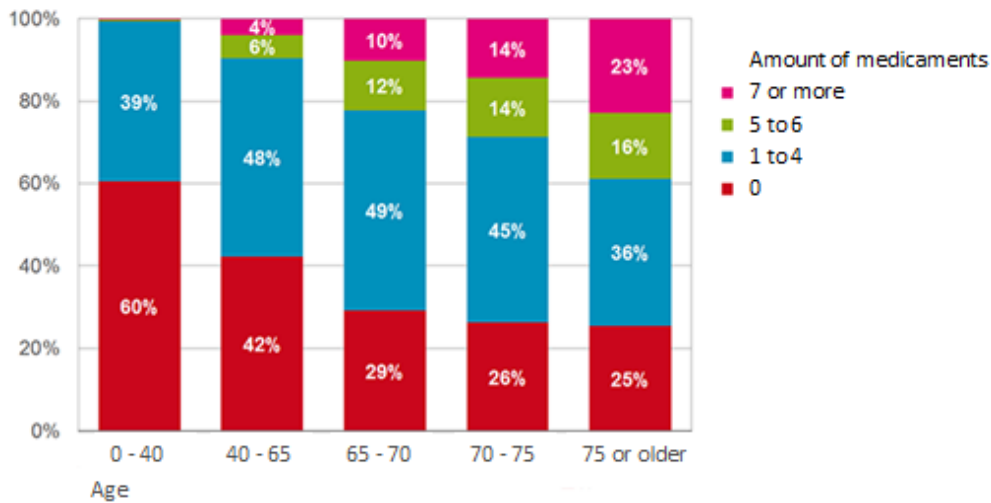


Figure 1. The percentage of pharmacy visitors in relation to the number of chronically used medication per age category in the Netherlands (adapted from Stichting Farmaceutische Kengetallen, 2014 <sup>[9]</sup>).

With the healthcare sector already being put under pressure by the increasingly ageing population and staff shortages, new strategies are needed to warrant the quality and safety of patient care. One of these strategies is to involve the group that is most at risk for potentially preventable medication errors; the patients themselves. Previous research has shown that patient participation could play a key role in reducing errors in prescribed medication <sup>[10, 11]</sup>. By providing patients with the opportunity to be involved in their medication (changes), this elicits positive benefits for the quality and safety of patient care. To achieve the standards for safe care around medications, set by the Dutch Health Care Inspectorate, it is important to give patients the opportunity to actively participate in medication management <sup>[11, 12]</sup>. By obtaining the patient's view on the in-hospital medication process and their role in it, a valuable step is made towards an effective reduction of in-hospital prescribing errors.

In 2016, The Netherlands National Institute for Public Health and Environment (RIVM) published a study on the perspective of frail older patients on safe care around medicine <sup>[12]</sup>. In this report, focus groups with patients and client organisations were conducted in which their opinion was inquired about their experiences concerning the current medication safety. It appeared that patients not always received sufficient information about their prescribed medication and were not fully informed about the side effects. In addition, the communication between the hospital and general practitioner was not always accurate, and it was unclear for the patient who was responsible for the overall package of prescribed

medication. Last, a part of the patients (especially those that used medication for a longer period of time) wanted to be more actively involved in the decision-making process, whereas the other part would rather leave this to their physician.

Although the study of the RIVM provides useful insights into the perspective of frail older patients with polypharmacy on the current medication safety, little research has been done on the patient's perspective on their own role in medication safety in a hospital setting. Therefore, it is important to inquire more information on how patients perceive their role in in-hospital medication safety and to what extent they would like this role to be different.

## 2. Research question

The aim of this study is to explore the view of older patients with polypharmacy on their role in medication safety in a hospital setting. The following research question will be answered:

What is the view of older patients with polypharmacy on their role in in-hospital medication safety?

In order to answer the main research question, it is essential to examine how patients perceive their current and preferred role in in-hospital medication safety and to what extent these match. Two important components for patient participation stand out, respectively the obtainment of medication-related information and the involvement in (decisions on) medication. When investigating the view of older patients on their role in in-hospital medication safety, it is important to take these key aspects of patient participation into account. Therefore, the following sub questions have been formulated:

1. How and to what extent would patients like to be *informed about* their medication?
2. How and to what extent would patients like to be *involved in decisions on* their medication?
3. What do patients perceive as their current and preferred role in in-hospital medication safety and to what extent do these match?

### **3. Theoretical Framework**

Within this chapter, the concepts of Patient-Centered Care (PCC) and patient participation are explained and related to the topic of medication safety. Both concepts highlight the importance of focussing on the patient's role in improving the quality and safety of medication-related care. Subsequently, Arnstein's ladder of participation is introduced and explained. Two core elements of the participation ladder, respectively information and decision-making, have been frequently mentioned in multiple models of PCC as major points of attention. Therefore, these aspects are elaborated on, to outline their impact on safe care concerning medication.

#### **3.1 Patient-Centered Care**

Over the last few decades, the provision of healthcare has made a drastic, fundamental change, moving from a traditional (paternalistic) approach to a patient-centered care (PCC) approach<sup>[13]</sup>. Where patients were first seen as passive subjects, following instructions or advice from a healthcare professional (HCP) without any questions or hesitations, they are now encouraged to take up a proactive role of being much more involved in the healthcare process concerning their own health<sup>[14]</sup>. The Institute of Medicine (IOM; committee on quality of healthcare in U.S.) defined PCC as ‘‘providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions’’<sup>[15]</sup>. In addition, the IOM put PCC as one of the six objectives for improving health care in the 21st century<sup>[16]</sup>. The PCC approach is integrated with many positive benefits, such as improved patient health outcomes, increased patient satisfaction with care, higher patient's adherence to treatment plans and an improved overall patient safety and quality of life<sup>[13, 17]</sup>.

#### **3.2 Patient participation**

Closely related to PCC is the concept of patient participation. Patient participation is defined as the patient's rights and opportunities to influence and engage in decision making about their own care through a dialogue attuned to his/her preferences, potential and a combination of their experiential and the professional's expert knowledge<sup>[18]</sup>. In accordance with PCC, patient participation is increasingly recognized as one of the main factors for improving the safety and quality of healthcare<sup>[19]</sup>. Although the concepts of patient-centered care and patient participation may come across as fairly similar, patient participation has to be viewed as the



strategy with which healthcare can become more patient-centered <sup>[20]</sup>.

### 3.3 Ladder of participation

In 1969, one of the most well-known models in describing the levels of public participation was established by Sherry Arnstein: the ladder of participation <sup>[20]</sup>. Although Arnstein's ladder traditionally aimed to provide an approach to analyse citizens' participation, it is now believed that the participation ladder provides a clear analogy that can be applied to different settings in which people participate <sup>[21]</sup>. In this research, the ladder of participation will be applied to the area of healthcare and the position of patient participation in in-hospital medication safety.

The ladder of participation consists of eight stages of participation, with each ascending step representing greater patient participation and autonomy. The two lowest rungs of the ladder are formed by non-participation, respectively manipulation (1) and therapy (2). Manipulation is characterized by a HCP aiming to cure the patient, whereas therapy is focused on educating patients towards changing themselves. The next three ladders are dominated by tokenism (the practice of making no more than a symbolic or token effort). Informing (3) is the first small step towards active participation, whereby HCPs inform the patients about their rights and options within the healthcare process. Secondly, consultation (4) embodies a more active participation in which the patient is consulted. In the highest rung of tokenism, the healthcare professional is actively involving the patient in the planning of care, but final decisions are still being made by the HCP. This is called placation (5). The upper three rungs on the ladder are formed by 'citizen' power. Partnership (6) is characterized by shared-decision making and a redistributed power balance amongst patients, their family and HCPs. Stepping on the next rung of delegated power (7), the patient holds predominant power, shifting to total power and control when climbing the last rung to 'citizen' control (8) <sup>[22]</sup>. In figure 1, the eight levels of the ladder are shown.

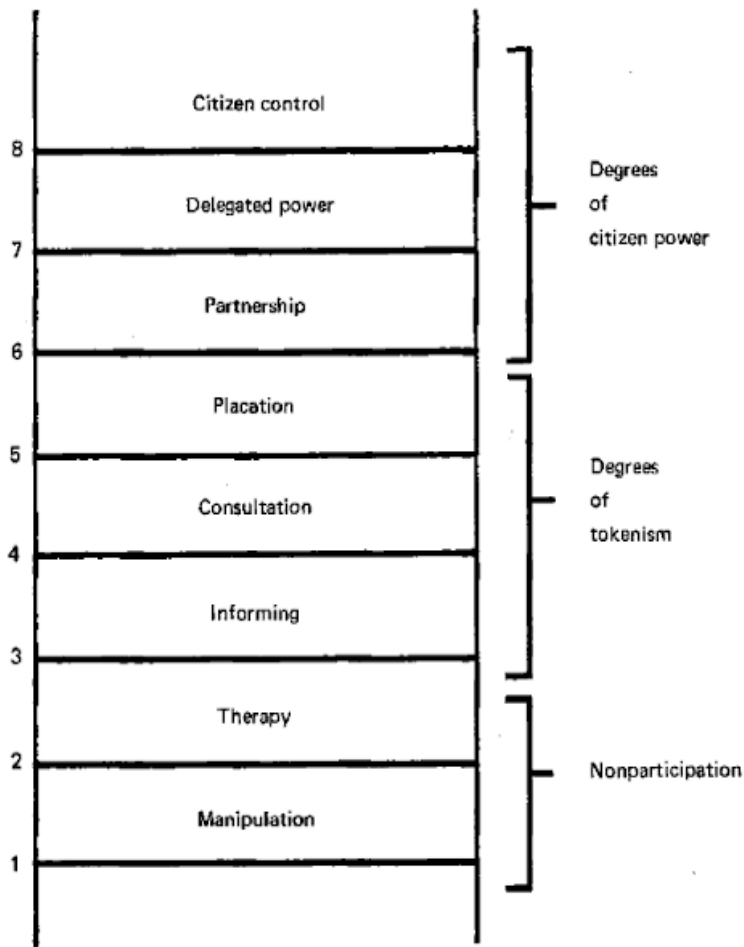


Figure 1. *Ladder of Participation* (from Arnstein, 1969)

Looking at Arnstein’s participation ladder, it appears that the aspects concerning i) information and ii) decision-making play an important role in determining which rung on the ladder the patient occupies. Since these two domains are frequently mentioned in various models that focus on PCC [23-27], it is important to touch upon these aspects and investigate them in literature.

### 3.4 Information

The domain of information emphasizes the importance of informing the patient on all relevant facts concerning their health (e.g. clinical status, progress, prognosis) to ensure the autonomy and ability to self-manage, and promote their own health. When fully informed, the patient will feel more empowered and take responsibility for elements of care within its own control [28]. It appears that patients perceive it as a strong barrier when the provision of information is insufficient [10-12, 28-30]. When patients experience a lack of knowledge and understanding of medication (changes), this causes strong information needs [11, 31]. In addition, many patients

are unaware of the in-hospital organisation structure and who is responsible for their medication <sup>[29]</sup>. Facilitators for medication safety in terms of information are the possession of knowledge, receiving information without specifically having to ask for it, repeating the information at multiple moments by the HCP and being encouraged to ask questions <sup>[28, 30, 32]</sup>.

### 3.5 Decision-making

When discussing decision-making in PCC, the concept of shared-decision making quickly arises. Shared-decision making is characterized by a decision making process that is jointly shared by both patient and HCP <sup>[33]</sup>. Especially in PCC, shared-decision making is increasingly seen as the ideal approach for doctor-patient encounters <sup>[34]</sup>. A study of Kugbey, Asante & Meyer-Weitz (2018) found that shared-decision making improves the corresponding doctor-patient relationship, subsequently improving the patient's quality of life <sup>[35]</sup>. This, again, underscores the need for increased patient involvement in medical decisions.

However, it appears that patients still often experience a lack of shared-decision making and a power imbalance between the HCP and the patient <sup>[13, 29]</sup>. The latter especially occurs when HCPs talk over the head of the patient, giving him/her the feeling of being outside and unwelcome. In addition, patients often feel being left outside by HCPs when they are not listened to or when they are not able to express their needs and wishes <sup>[29]</sup>. Contrary to this, patients feel enabled through close involvement in the decision-making process, giving people a sense of being in control <sup>[10, 32]</sup>.

Since the aspects of information and decision-making are major components in this study, the above-mentioned literature is taken into account to further investigate the patient's view on their own role in in-hospital medication safety. These findings are useful in determining where the patients are currently situated (according to themselves) on the ladder of participation, what their preferred position is and to what extent these two match.

## 4. Method

In order to answer the research question that has been presented in this study, qualitative research was conducted. Semi-structured interviews have been carried out in order to explore to what extent patients would like to be informed and involved in (decisions on) their medication and how patients perceive their current and preferred role in in-hospital medication safety. In this chapter the study design, data collection and data analysis are discussed.

### 4.1 Study design

Participants for the semi-structured interviews were recruited via purposive sampling in the Jeroen Bosch Hospital (JBH: 856 beds) at 's-Hertogenbosch, the Netherlands. Initially patients were recruited via nursing staff, handing out invitation forms to all patients on the participating wards, consisting of general surgery, urology, internal medicine and cardiology (see Appendix A). However, this did not yield any partaking in the study. Therefore, a more personal approach was chosen in which one researcher (IK) personally approached patients for participation during their hospitalization. Patients were approached when they complied with the following criteria: a) aged 75 years or older, b) daily use of  $\geq$  ten medicaments, and c) admission of at least 24 hours to one of the participating wards. The inclusion criteria were determined by a team of researchers (IK, EK, KS and RM). These patients were thought to be more vulnerable for medication incidents and medication-related hospital admissions in comparison with elderly 65 years with five or more different medications. Patients who suffered from dementia or other cognitive impairments, causing the inability to be interviewed, were excluded from participation. In addition, patients with the inability to speak or understand the Dutch language were excluded as well.

Patients, that were willing to participate in the study, were asked permission for writing down their contact details. Once the patients had been discharged from the hospital for a few days, they were contacted to schedule the interview. Over a period of six weeks, approximately 40 people were approached to participate in the study. For a variety of (personal) reasons, the majority wished not to participate. In addition, some patients that initially indicated to be willing to participate were excluded because of later illness or readmission in the hospital. Due to the low response rate, the choice was made to ease one of the inclusion criteria. Therefore, patients with a daily use of seven or more medicaments were

included, instead of the original criteria of ten or more medicaments. Eventually, a total of ten participants were included in the study.

## **4.2 Data collection**

Before the start of the study, a short survey was set out in the JBH Digi-panel. The Digi-panel of  $\pm$  1000 members, consisting of JBH-(ex)patients and caregivers, had a response rate of  $\pm$  20%. In the survey, the member's opinion was inquired about prescribed medication during hospital admission and their corresponding information needs- and wishes. Based on the results of this JBH Digi-panel survey and the input from the theoretical framework, a topic guide was developed by a team of researchers (IK, EK, KS, RM and KK). In this topic guide (see Appendix B), important themes were listed from which interview questions were derived to determine the patient's perspective on their role in in-hospital medication safety. During the iterative process of data collection, small adaptations to the topic guide were made to further elaborate on certain aspects. These adaptations have been processed in the topic guide (see footnote Appendix B). Since new additions were not discussed with all interviewees, it is possible that findings are presented which do not cover a total of ten interviews.

Before the interviews were conducted, two pilot interviews took place in order to test the topic guide and gain experience with interview techniques. The semi-structured interviews were carried out after hospital discharge at the patients' homes. All participants were interviewed by one researcher (IK). Prior to study commencement there was no relationship between the researcher (IK) and participants. In total, ten semi-structured interviews have been conducted, of which all were included in the data analysis. Prior to starting the interview, patients were asked for informed consent. An informed consent form provided participants with information on the study design, its main objectives and the storage of data (see Appendix C). Participants were given time to ask any study-related questions and were requested to sign the informed consent. This informed consent also included permission to audio record the interview. In addition to the audio recording, handwritten notes were made during the interview for remembering key information. The average interview time was approximately 20 to 30 minutes per patient.

## **4.3 Data analysis**

Transcription of the interviews took place within two days of conducting the interview itself. Interview transcripts were transcribed in the spoken language (Dutch) and transported to the

qualitative data analysis software Atlas.ti version 8 to (anonymously) store, code and analyse the interviews. The interviews were coded by the three-step process of coding: open coding, axial coding and selective coding <sup>[36]</sup>. Open coding is characterized by an initial selection process of the raw data. Relevant text fragments were labelled with codes that covered the content of the indicated text. In this way, text fragments addressing the same topics or issues were provided with identical codes. The first five interviews were used to create an initial pool of codes via open coding. During the second phase, axial coding, the existing codes were furtherly examined, complemented, merged, structured and grouped. Via this way, main and subcategories were identified. During the final step of the coding process, selective coding, the underlying connections between the (sub)categories were identified and interpreted. In addition, differences or similarities between respondents were compared and further analysed. By doing so, selective coding formed the start of the theory induction in which main themes, sub themes and interconnections were identified, providing valuable insights in the patient's perspective on in-hospital medication safety. The open and axial coding were executed by two researchers (IK and EK). After separately coding the first interviews, the researchers met prior to selective coding for reaching consensus about a code dictionary in which (sub)categories were identified. This code dictionary was further complemented, separately by both researchers, with additional codes due to new insights from later interviews. In appendix D, the complete code vocabulary is shown (see Appendix D).

#### **4.4 Ethics**

This study was conducted in accordance with the principles of the Declaration of Helsinki <sup>[37]</sup>. Participation in this study did not entail any potential risks to the participants. The participants were given an information- and consent form on paper (and digitally, if requested), providing them with full details of the study (Appendix A, Appendix C). The informed consent form included information on participation in the study and the storage of data. In order to maintain the privacy and preserve confidentiality of the participants, responses have been handled and stored anonymously.

## 5. Results

In this chapter, the results are discussed and divided into eight paragraphs: the sample description (5.1), medication management in the hospital (5.2), medication changes (5.3), information and questions (5.4), involvement in (decisions on) medication (5.5), role of the patient (5.6), role of the hospital (5.7), and (example) medication error (5.8).

### 5.1 Sample description

A total of ten interviewees participated in the study. A summary of the sample description is shown in table 1. The interviewees were equally divided into males ( $n = 5$ ) and females ( $n = 5$ ). The mean age of all interviewees was 80.9 years ( $SD = 5.2$ , range 75-90 years). The level of education amongst the interviewees was varied. One fourth of the interviewees attended (extended) elementary education ( $n = 3$ ), whereas the majority ( $n = 4$ ) attended intermediate vocational education ( $n = 4$ ), followed by higher professional education ( $n = 2$ ) and university ( $n = 1$ ).

The participants were admitted to one of the four participating wards, respectively general surgery ( $n = 3$ ), urology ( $n = 2$ ), internal medicine ( $n = 2$ ) and cardiology ( $n = 3$ ). On average, the interviewees had a hospital admission of 9 days ( $SD = 6.9$ , range 1.5 - 28 days). Of all interviewees, the majority ( $n = 8$ ) stated to have proper knowledge about their own medication. Only two interviewees ( $n = 2$ ) indicated not to be aware of the medication they had to take, both at home as in the hospital.

The interviewees varied in terms of their medication management at home. The study sample included seven patients that took their medication independently. Of these seven interviewees, some organised their medication on a daily basis ( $n = 4$ ), whereas others made use of a weekly pill organiser ( $n = 3$ ). The remaining interviewees either were dependent on a caregiver in providing them medication ( $n = 1$ ) or used a Baxter-medication roll ( $n = 2$ ). A Baxter-roll is home-medication that has been pre-packed by the pharmacist in small packages, indicating the time at which medication needs to be taken.

To be included in this study, the participants had to comply with the inclusion criteria of a daily use of seven or more different medicaments. At the time of conducting the interviews, the majority of the interviewees used between seven and fourteen different medicaments on a daily basis ( $n = 9$ ). One person had a daily use of more than fifteen different medicaments.

Table 1: Characteristics of participants (n = 10)

<b>Patient</b>	<b>Sex</b>	<b>Age (years)</b>	<b>Number of different medicaments at home</b>	<b>Medication management at home <sup>a</sup></b>	<b>Knowledge of own medication</b>	<b>Education</b>	<b>Hospital length of stay (days)</b>	<b>Ward</b>
1	Male	76	15	Baxter <sup>b</sup>	No	(Extended) elementary	21	Cardiology
2	Male	86	13	Independent daily organisation	Yes	Intermediate vocational	9	Cardiology
3	Female	78	12	Independent weekly organisation	Yes	Intermediate vocational	8	General surgery
4	Female	89	8	Independent daily organisation	Yes	(Extended) elementary	4	Internal medicine
5	Male	90	7	Independent weekly organisation	Yes	(Extended) elementary	10	Urology
6	Female	78	11	Independent daily organisation	Yes	Higher professional	4	General surgery
7	Female	75	9	Independent daily organisation	Yes	University	7	Internal medicine
8	Male	78	11	By partner	No	Intermediate vocational	10	Cardiology
9	Female	78	8	Independent weekly organisation	Yes	Higher professional	1.5	Urology
10	Male	81	12	Baxter <sup>b</sup>	Yes	Intermediate vocational	6	Internal medicine

<sup>a</sup> according to patient <sup>b</sup> pre-packaged medication roll (provided by pharmacist) for home-use



## 5.2 Medication management hospital

Prior to the interview, all participants were asked to describe the medication management in the hospital. In the Jeroen Bosch Hospital, self-management of medication is allowed when the patient self-manages medication at home, speaks and understands Dutch, and is physically and mentally capable and willing to manage medication. In total, six interviewees had their medications taken over by hospital staff. The other interviewees (n = 4) could, in consultation with hospital staff, self-manage their own medication. If new medication was prescribed during the hospital admission, this was managed by hospital staff. When the interviewees were asked about their preferred medication management during hospital admission, four people indicated to prefer the hospital to take over. As one interviewee stated:

*“No, I wouldn't do it. No, no, I prefer to leave it to those people [hospital staff]. They pay attention to it the entire day, and for me... I'm lying there when I don't feel a 100%. Look, and then I think self-managing medication is a bit... yes, irresponsible, let's put it that way.”* (male, 86).

Amongst the interviewees that wished to have their medication managed by the hospital, feeling sick and not competent enough was the main reason for not self-managing their medication. The take-over of medication was experienced to be pleasant as interviewees often felt sick and miserable during their hospital admission. For most, it was a relief that they did not have to focus on their medication while feeling unwell. In contrast, there were four interviewees that preferred to self-manage their medication during hospital admission. All of these interviewees had self-managed their medication during their last hospital admission. Some of them indicated to be bothered by a possible medication take-over. One of the most mentioned reasons for preferring self-management over hospital-management was the importance of controlling your own medication. Apart from keeping yourself vigilant, the interviewees thought it was important to care for your own body and saw it as a way to prevent mistakes. In addition, when patients were admitted in the hospital they were often provided with slightly different medications than the ones they have at home. For some patients this can be a real problem:

*“I'm very much affected when they change the medication here [the hospital]. That's why I prefer to take my own things, I know those won't make me sick.”* (male, 90).

Within this group of self-managers, a difference was made between managing old and new medication. The majority indicated a preference for taking familiar medication themselves, while new medication should (initially) be managed by hospital staff. Other individuals stated not to have a preference in medication management during their hospital admission (n = 1), or were convinced that they did not have a say in the matter and were forced to give their medication out of hands (n = 1). It is interesting to note that the extent to which medication was being managed at home was in line with the hospital's medication management. The majority of those, that already gave away control of their medication at home, were more positive about the hospital managing their medication in comparison to those who actively managed their medication at home.

### 5.3 Medication changes

All ten interviewees had changes in their medication during hospital admission. These medication changes could imply a (temporary) start or stop of medication, a change in the way of administering medication or a combination of the above. The majority of the interviewees (n = 7) had been informed about these changes. Two interviewees indicated not to have had any information about medication changes, of which one stated:

*“You know what it is? When they change something in the hospital, for example for the blood pressure or something, they don't tell you that! They just change it and they don't tell you.”*  
(male, 76).

Multiple interviewees (n = 3) addressed the importance of informing the patient about medication changes. However, there was a large distinction in patients inquiring after the medication changes. Some interviewees did not ask for an explanation if changes in their medication occurred. One interviewee (male, 76) explained this by saying: *“the less [medication] I got, the better”*. Whereas another interviewee (female, 78) was actively inquiring: *“what am I getting?”*. Especially the first group embodied trust in professionals when changes in medication were made:

*“I expect that when I receive that medication, it is correct”,* (female, 78).

During discharge, a discharge conversation about medication is held with the patient. Five interviewees had had a medication discharge conversation in order to receive information

about medication that had been started or stopped. The medication discharge conversation was executed by either a physician or pharmaceutical assistant. Six interviewees indicated that clear info was provided about their medication during their overall hospital admission. However, one interviewee had missed crucial information about side-effects of medication.

## 5.4 Information and questions

The information provision about medication seemed to vary per interviewee. Although the majority indicated to have had sufficient information, sometimes these interviewees has still missed certain information. Participants missed the following aspects of medication-related information: the type of medication, the reason for prescribing, the mechanism of action, the fabric- and brand name, and important side-effects. Often, when specifically asking for information, the hospital staff provided the patient with a clear, extensive explanation. No differences in information provision were detected amongst the various hospital wards.

Most information was provided orally when the patient was lying in bed. Sometimes, information about medication was communicated via paper, but interviewees viewed this as not having much added value or quickly perceived it as too tiring to read when feeling unwell. Especially when a medicine was only temporary, oral information was perceived as sufficient. When asked which way of information provision the interviewees preferred, half of the interviewees (n = 5) suggested oral information. A partner of an interviewee noted that she would find it useful when information was provided on paper. Since her husband did not have any knowledge of his own medication, hospital staff continuously had to return when the interviewee's partner was present to share the information with her. Information on paper would have been more efficient for participant and partner, but also for the hospital staff. Almost all interviewees (n = 7) thought it was important to be informed about new or changed medication. However, for some interviewees (n = 2) being informed would not contribute much as they claimed to quickly forget the information they received. These interviewees also seemed to be patients that have full trust in healthcare professionals, making them fairly indifferent to the information they receive. In accordance, this can be seen in the type and amount of questions asked. When inquiring for the reason of asking relatively few questions, answers such as *"I trust the physician"* (male, 76), *"I wanted to go home"* (male, 90) or *"I was glad that I could leave"* (female, 78) were provided. One interviewee even expressed to experience difficulty in asking questions during his hospital admission:

*"I'm not someone who continuously keeps asking. I'm not a whiner, let me put it like that. I*

*would rather have them coming to me to say it.” (male, 86).*

Overall, the majority of the interviewees (n = 6) indicated to ask questions when they would not understand something and felt there were sufficient opportunities to do so during their last hospital admission.

## **5.5 Involvement in (decisions on) medication**

When exploring the current involvement of the interviewees in (decisions on) medication during their hospital admission, it appears that half of the interviewees (n = 5) felt involved. In answer to the question how they felt involved, this feeling was mainly based on hospital staff actively inquiring for the patient’s well-being and acting on it. In addition, interviewees felt involved when they were informed and involved in their treatment plans and when their questions were properly answered. Four interviewees indicated not to have been involved, of which one interviewee did not recall any involvement. Remarkably, seven out of ten (both involved and uninvolved) mentioned the trust in their healthcare professional. There appears to be a large confidence of patients in healthcare professionals, with multiple interviewees indicating that *“the professional will do what is best for me”*. Multiple explanations were given for this faith in the healthcare professionals. Firstly, interviewees indicated not to have any knowledge about medication (n = 5):

*“They just said: we’re going to do this and that. No, yes, okay.. that’s fine. I can’t decide whether that’s right or not. I obviously don’t know. I didn’t go to med school, so I put my trust in them.”, (male, 86).*

Another reason for having little to no involvement concerned the necessity to take medication (n = 2). These patients stated to be aware of the fact that they were in the hospital for a reason and therefore needed treatment. Decisions on their medication were, for that reason, not something to argue about.

*“Look, they prescribe those things and you obediently take them. It’s as simple as that.”, (female, 78).*

In addition, the improvement of personal health as a result of the healthcare professional's actions and decisions was taken as a bench-mark (n = 3). These interviewees indicated that once they felt better, they were satisfied and did not need more involvement.

In terms of the preference for involvement it appears that interviewees (n = 5), who felt involved in their previous hospital admission, preferred to maintain this level of involvement. Reasons for wanting to be involved focused on the importance of knowing the medication that you are taking and control over your own body. Interviewees who felt uninvolved did not have a preference to be more involved. The main reason for this was the lack of medical knowledge. In accordance with the extent of involvement, was the extent of shared-decision making. The interviewees that indicated a preference for involvement also had a positive attitude towards shared-decision making. Some interviewees (n = 3) had past experiences with shared-decision making, of which most entailed decisions on continuing or stopping certain medication. One interviewee even stated that, during her previous hospital admission, the physician let her decide whether or not she wanted to be operated on, which she experienced to be positive:

*“Another person should not impose something on me. But this was an open conversation, and the possibility occurred...”, (female, 78).*

The interviewees that had not been involved and did not have a preference for being involved, indicated not to be able and willing to participate in shared-decision making. Again, the lack of medical knowledge was the main reason for not participating in this process.

## **5.6 Role of the patient**

During the interviews, different patient-roles came forward. Out of the ten interviewees, three people clearly displayed a passive patient role, three people embodied an active patient role and the remaining four participants found themselves somewhere in-between passive and active (intermediate). The interviewees brought forward different activities to fulfil a role in medication safety, varying in the extent of involvement. For example, some interviewees indicated to read information leaflets (n = 1), monitor their own health while being admitted (n = 2) or state (physical) complaints to HCPs (n = 2). Others searched information about medication online (n = 2), reminded HCPs of providing them with medication (n = 2) or independently checked the medication they were given (n = 5). As one interviewee stated:

*“Sometimes I doubt if they did it right [providing the correct medication]. I always check if they did it right or not. I know exactly what I should get, so I check if they.. if it’s another colour I will say so immediately”, (female, 89).*

It appeared that not only knowledge of, but also personal experiences with disease(s) and medication were of great importance in the determination of the patient’s role. One interviewee had been ill for many years and therefore knew exactly how her body responded to certain medication. She perceived it to be difficult to give away control over her medication. Besides, previous experiences with errors or faults had made her extensively alert:

*“I always tell everybody who has to go to the hospital: Sit up straight in bed and pay close attention!”*, (female, 75).

Looking at the preferred role of the patient, the majority of interviewees did not think they could contribute much to medication safety. For these interviewees (n = 6) this is mainly caused by the lack of knowledge on medication and the desire to return home as quickly as possible. The active patients (n = 3) indicated to fulfil a role in improving in-hospital medication safety by asking more information about (decisions on) medication. Furthermore, they stated to be more alert in checking their received medication in order to prevent medication errors.

When comparing the patient’s roles with the demographic characteristics of the interviewees, some interesting findings stand out. The interviewees who embodied a passive patient role relatively had the lowest educational level in comparison to the other interviewees. In contrast, the three active patients followed either higher professional or scientific education. In addition, the three passive patients were all male, whereas the active patients were female. Within this study sample no outstanding differences in patient roles were found concerning age. Furthermore, some interviewees (n = 2) indicated that the patient’s health status was an important benchmark in fulfilling a certain role. These participants were aware of the fact that a good health and clear mind were not self-evident and acknowledged that this could not be expected of every patient.

*“I think you can’t do it like this with everyone, because there are people that have no knowledge, no understanding. And they just take whatever medication is being given to them.”, (female, 78).*

Overall, the results of this research seem to suggest that the role of the patient could possibly be intertwined with various factors, including level of education, gender, health status, length of- and experiences with disease(s).

## **5.7 Role of the hospital**

The current role of the hospital is, according to the interviewees, divided into positive and negative aspects. The majority of interviewees (n = 7) stated to highly appreciate the feeling of being heard by healthcare professionals. This could either be HCPs taking notes when interviewees actively indicated complaints, but also responding to the patient’s questions or worries. When interviewees felt that sufficient time was taken to reassure the patient, this was experienced as positive. Besides, one interviewee felt that healthcare professionals were increasingly opening up to the idea of shared-decision making and had a higher acceptance of patients taking up this active role. In contrast, there were also interviewees (n = 3) that indicated to feel belittled or not heard by healthcare professionals. An interviewee stated an example:

*“Once I was a bit panicked. It was when I had severe headache. I said “doctor, I have such a severe headache”, “Yes, we’ll look into that, but you’re not here at the neurology department, you’re at the cardiology”. As if he wanted to say, this headache...”, (male, 76).*

In addition, two interviewees indicated to have had different physicians during their hospital admission, whereas they preferred more continuity in the person treating them. When looking at the desired role of the hospital, a preference for personal contact with the physician is found. According to one interviewee, having the same physician during hospital admission would contribute to a higher overall feeling of trust. Furthermore, it seems that communication towards patients should be one of the hospital’s main points of improvement. These points are characterized by providing the patients with sufficient information (n = 5), communicating actions (n = 4), listening to the patients’ needs and wishes (n = 3) and taking patient’s complaints seriously (n = 2).

*“Communication is not the strongest point of most physicians. I told them “you just have to give more information and transparency! [...] They don’t listen to my complaints and then I think: listen up you, I’m 78 years old and I can feel my body best“, (female, 78).*

Moreover, some of the interviewees (n = 2) addressed a need for improving regularity in the provision of medication. Last, since certain medication or other supplements were often not in stock, interviewees (n = 3) would appreciate more assistance from the hospital with follow-up services to make sure medication-related aspects are well arranged after discharge.

### **5.8 (Example) medication error**

All interviewees (n = 10) indicated not to have experienced medication errors in the period after discharge from the hospital. During their admission, six interviewees stated not to have experienced medication errors, whereas four interviewees thought they did. These medication errors either implied receiving medication too late (n = 2), receiving the wrong medication (n = 1) or receiving the wrong prescription for medication (n = 1). Due to later adaptations of the topic guide concerning medication error(s), seven out of ten interviewees were presented with an example medication error. Of these seven interviewees, a slight majority (n = 4) preferred to be informed about a possible medication error, even when there were no damaging effects to the interviewee. Explanations of these interviewees focused on the importance of transparency. The other participants (n = 3) stated not wanting to be informed when a medication error, which would not cause them harm, was made. As one interviewee explained:

*“If I don’t feel anything I don’t have to ask about it, do I?”, (male, 78).*

In terms of the patient’s role in medication errors, two interviewees thought there should be an active role for the patient in reducing medication errors. This active role could be achieved by paying close attention and actively inquiring about medication they receive or should have received. However, both interviewees also indicated an active role for the hospital in improving their job to prevent these, often preventable, faults from happening. In contrast to these two interviewees, there were others (n = 3) that did not see a role for the patient in reducing medication errors. These patients indicated to trust the expertise of hospital staff and could not imagine how patients could contribute in any way.

A remarkable finding was the overall understanding for making errors. Most of the



interviewees (n = 6) indicated to view that making errors is human. However, since these errors concerned health, interviewees did also state that healthcare staff had to be extremely careful in their actions. One patient confirmed this by saying:

*“When I made a mistake in my former job, I had to acknowledge it. Everyone makes them [mistakes]. And I’m not the person to directly judge people, but health is of course something different than material things.”, (female, 78).*

The overall feeling when a medication error did (or possibly would) occur, was experienced as unpleasant (n = 5). In contrast, two other interviewees stated that they would not be worried as long as they were informed about the error. When interviewees looked back on their last admission in the hospital the majority (n = 6) indicated to have felt safe. One interviewee seemed to capture the overall feeling by stating:

*“Well, I have to say I didn’t feel unsafe at this ward. I also told them: “I have a safe feeling, I feel you are qualified, but there are some little footnotes”, (female, 75).*

## 6. Discussion

The aim of this study was to explore the view of older patients with polypharmacy on their role in medication safety in a hospital setting. This section provides answers to the sub-research questions using the key findings of the semi-structured interviews. These findings are discussed in relation to the theoretical framework (see chapter 3) and additional literature. Thereafter, strengths and weaknesses of the research are brought forward, followed by recommendations for future research.

### 6.1 How and to what extent would patients like to be informed about their medication?

The results of this study show that almost all participants indicated to hold a preference for being informed. Overall, most interviewees had been informed about medication changes during their last hospital admission. The wish to be informed mostly concerned medication changes. The interviewees mentioned that preferred information included the reason for prescribing different or new medication, the type of new medication, its way of functioning and important side-effects. These results seem to be in agreement with the findings obtained by Redley et al. (2018), indicating that patients appreciate medical information being shared with them <sup>[38]</sup>. In addition, several studies found evidence that information was an important factor for patient participation as it made patients feel informed, engaged and respected <sup>[39-40]</sup>.

In terms of information provision, the extent to which patients would prefer to receive information about medication differs per person. In this respect, there are three broad patient roles to be distinguished: i) active, ii) passive and iii) intermediate. Patients that occupied an active role seemed to prefer receiving more information about their medication than patients that were fairly passive. The latter were mainly focused on going home as quickly as possible while embodying a large trust in HCP's. This association is also found in the study of Eibergen et al. (2018), indicating that one of the main reasons for not wanting information is based on the patients' trust in their HCP <sup>[41]</sup>. Besides, some interviewees in the current study indicated to quickly forget medical information which they received during their admission.

Previous studies have indicated that patients seek clear and contextualised information at a comprehensible level <sup>[28, 42]</sup>. However, it is also stated that healthcare professionals find it difficult to balance the information provision of medication risks, while possibly increasing the patient's worries and fears <sup>[42]</sup>. In this research, it is interesting to note that the majority of interviewees highlighted the importance of receiving (understandable) information and

transparency, even when this concerned possible medication errors. In terms of asking questions about information, the predominantly passive patients were found reluctant to actively ask information when it was not automatically provided. This finding is in accordance with that of Ringdal, Chaboyer, Ulin, Bucknall & Oxelmark (2017), stressing the patient's desire to receive information from HCPs without having to ask for it <sup>[28]</sup>. Although the active interviewees did not experience difficulty in asking questions when something was unclear, one could imagine that a universal preference exists for receiving information without having to ask for it. Furthermore, it is interesting to note that oral information provision was perceived to be the most pleasant by the majority of interviewees. Although the communication between patients and HCPs generally occurs orally, Mohsin-Shaikh, Garfield & Franklin (2014) found that patients encounter trouble absorbing oral information during their hospital admission <sup>[10]</sup>. Oral information can, particularly in special circumstances such as hospital admissions, easily be forgotten. Therefore, HCPs have to take this into account when providing information to the patient and check whether or not the patient has correctly understood and remembered important information.

When looking at the ladder of Arnstein (see chapter 3), "informing" is the third level (out of eight) of patient participation <sup>[22]</sup>. This rung is defined by HCPs informing the patient about, among others, treatment plans and the patient's medication. In order to move a rung up the ladder, towards the level of consultation, the patient needs to dispose of sufficient information in order to be consulted. Hence, informing the patient is a requirement for establishing this transition, in which a shift is made from a traditional, paternalistic approach towards patient participation and thus patient-centered care. The interviews have shown that patients would like to be provided with information on their medication, although the extensiveness of preferred information might differ per patient. Informing the patient is the task of HCPs, who need to be aware of the importance of their role in educating the patient about their medication.

## **6.2 How and to what extent would patients like to be involved in (decisions on) their medication?**

In terms of the overall involvement of patients during their hospital admission, most of the interviewees felt involved. This feeling of involvement was mainly based on staff inquiring after the patient's health, staff informing the patient about medication (changes), communicating treatment plans and/or possible changes in treatment or medication. In terms of the involvement in medication, it seemed that similar patient roles (active, passive,

intermediate) were found in the same interviewees as found in the information provision. The active group was characterized by patients having a high involvement. These interviewees expressed the importance of being aware of the medication they were taking since it involved their own body. On the contrary, the passive patient group was fairly uninvolved and mainly trusted the HCPs in their decisions. Reasons that were brought forward included a lack of knowledge in combination with the necessity of taking medication, and the improvement of health as a benchmark. The intermediate group displayed characteristics of both active and passive involvement. These observed differences of patient involvement are in line with those found by Vaismoradi, Jordan & Kangasniemi (2015), who executed a systematic review on patient participation in patient safety. In their study, similar results were found which indicated that most patients view patient participation as favourable and accept an active patient role by asking questions, reporting observations and being engaged in safety practices. However, there are also patients that prefer to withhold themselves from active participation, since they do not view this as their role and willingly hand over control to HCPs <sup>[32]</sup>.

This division of patients' involvement in medication is also found in the management of medication, both at home and in the hospital. Most of the active patients who managed their medication at home continued to do this during their hospital admission (if the opportunity was provided). It should be emphasized that the rate of interviewees that self-managed their medication during hospital admission was found to be quite high (40%). It is expected that this rate will be lower in the total study population of older patients. The self-management of medication was experienced as pleasant due to the preference to care for their own medication, keeping up-to-date with medication and preventing possible medication errors. These patients were also in favour of shared-decision making or already did so. The findings support previous research showing that patients, who are knowledgeable about patient safety and familiar with their own care and medication, are more likely to engage in patient participation <sup>[43]</sup>. A part of the patients that used to self-manage their medication at home were in favour of giving the medication out of hands during their admission. This preference for a medication take-over by the hospital was mainly based on the deterioration of personal health and feeling unwell, confirming that a patient's health status is crucial for patient participation <sup>[32]</sup>. The predominantly passive patients who had already given away control over their medication at home, continued to do this while being admitted in the hospital. In addition, these interviewees indicated not wanting to be involved in decisions about their medication as they barely had any knowledge about medication.

A transition towards a higher involvement, including shared decision-making, is not only dependent of the patient. Healthcare professionals fulfil an important role in order to achieve the level of partnership, being the sixth rung on the ladder of Arnstein. Partnership is characterized by shared decision-making and a redistributed power balance amongst patients, their family and HCPs <sup>[20]</sup>. A research of McTier, Botti & Duke (2015) indicated that hospital staff often does not make optimal use of the opportunities to involve patients in their medication management during hospitalization <sup>[11]</sup>. Important factors include a lack of time with patients, a focus on the task of administering the medication rather than on information provision about the medication, and the lack of conviction about possible benefits of educating patients while hospitalized. In agreement, the Netherlands National Institute for Public Health and Environment also indicated a perceived lack of shared decision-making by patients, stating that they were too little involved by HCPs in decisions concerning their medication and medication management <sup>[12]</sup>. Arnstein's ladder shows that the involvement of patients could vary from level one to eight, ranging from patients who do not wish to be involved to patients independently taking decisions against professional medical advice. Which place on the ladder a patient occupies is dependent on various factors, both internal and external. These include, among others, the patient's health, knowledge and experience of their own body and illness, but also depend on the HCPs and their attitude and beliefs towards patient participation. In order to achieve a growing patient participation, it is essential that both parties openly communicate the topic of patient involvement. In striving towards patient-centered care and an improved medication safety, both patient and HCP need to invest in patient participation.

### **6.3 What do patients perceive as their current and preferred role in in-hospital medication safety and to what extent do these match?**

In line with the previous discussed topics, the division of patient roles in in-hospital medication safety recurs into the same three categories of active, passive and intermediate. However, there appears to exist a difference in how patients perceive themselves on the continuum of activeness. Some interviewees assign themselves an active role when reading information leaflets or stating (physical) complaints to nursing staff, whereas this was seen as fairly passive by other, more active interviewees. The latter viewed an active patient role as reminding staff about medication that should be given or checking the medication they had received. In terms of the patient's preferred role, the active group indicated to improve

medication safety by increasingly asking for information and checking medication. The more passive patients indicated not to see a role for the patient in medication safety, as they did not embody sufficient knowledge about medication.

In the current study, the role of the patient seems to be connected to various factors, including the level of education and gender. In addition, health status, length of- and experiences with disease(s) also came forward as influencers that potentially could determine the patient's role. In literature, age was often mentioned as an important indicator [10, 43-44]. The study of Mohsin-Shaikh et al. (2014) indicated that those under 65 have been shown more likely to be involved in medication safety and medication management [10]. However, this study, including participants of 75 years and older, did not indicate a possible relation between age and the patient's role. A remarkable, recent finding of Sahlström, Partanen, Azimirad, Selander & Turunen (2019) indicated that patient-related factors such as age, educational level and gender do not explain increases in patient participation or patient safety as adequately as HCP-related factors [45]. Their research suggests that patient involvement is much more determined by the extent to which HCP encourage patients to participate and provide them with comprehensible information than demographic patient factors.

When patients were asked about the role of the hospital in medication safety, the interviewees seemed to have an unambiguous perspective. Answers focused on the patients' desire to be listened to, taken seriously in their complaints and communicated with about treatment plans or possible changes. During the interviewees' hospital admissions, mixed experiences of these aspects (both positive and negative) were brought forward. This indicates room for improvement in which the relationship between patients and HCP is an essential requirement for patient participation and patient safety [28, 45]. In order to reduce potentially existing power imbalances between HCPs and patients, HCPs should prioritize listening to patients and their needs [10]. Since patients often have years of experience with their disease(s) and corresponding medication, they would like to be more acknowledged and valued by HCPs [12]. Accordingly, HCPs will need to check to which extent a patient is able and willing to be involved in their medication, and possibly even in shared decision-making. Since there exist a certain risk in HCPs misjudging the patient's desire for involvement, HCPs will have to act carefully in order to prevent misconceptions by pigeonholing patients into certain roles [33].

## 6.4 Strengths and weaknesses

A strength of the current study includes the new insights that have been gathered regarding the view of older patients with polypharmacy on their role in medication safety in a hospital setting. Whereas many studies focus on an often broad and younger patient group (younger than 65 years), this study represents the perspective of more vulnerable, older patients in the Netherlands. Although this patient group has been studied before in relation to medication safety<sup>[13]</sup>, this research particularly investigated the perspective of older patients on their own role in medication safety, distinguishing it from previous studies. Secondly, at the time of recruiting patients on various wards, all patients that complied with the inclusion criteria were approached for participation. This prevented the occurrence of selection bias in the recruitment of participants. In addition, the semi-structured interviews took place at the homes of the patients, contributing to a safe environment for patients to share their opinions and experiences concerning their most recent hospital admission and discharge.

Another strength of this research concerns the theoretical framework. Especially Arnstein's ladder of participation contributed to a better understanding of the view of older patients on their role in in-hospital medication safety. Insights were provided into the current position of patients on the participation ladder and their preference for change. In this study, the ladder of participation has not been deployed as a tool to strive towards total patient control as this being the ultimate goal. Merely did it offer support and guidance in the different positions that patients could uptake and the requirements for reaching these positions.

The current study also consists of limitations. Firstly, the study sample was relatively small. Although data saturation most likely has been reached with ten interviews, conducting additional interviews would give more confirmation that the gathered data was saturated. However, due to time constraints this was not possible. Besides, two wards were not fully represented since only two interviewees per ward were included, whereas the other two wards included three interviewees. In addition, the percentage of patients that self-managed their medication during hospital admission was found to be quite high in comparison to the total study population. In combination with the relatively low participation rate, this could possibly indicate that a participation bias has occurred, making the study sample no complete representation of the total study population. In addition, the study took place in one hospital in which all patients were recruited. It is difficult to say to which extent the findings of this study can be extrapolated to patients in other (Dutch) hospitals. Furthermore, the views of patients who did not speak Dutch or were too unwell to participate were not represented in this study.

## 6.5 Recommendations for future research

In the following months, this research will be followed-up by a quantitative study on the same topic, concerning the perspective of older patients with polypharmacy on medication safety in the hospital. The main themes and findings of this study are used to develop a survey questionnaire which will be sent to a large, representative sample group of older patients with polypharmacy. Via this way it is possible to check if the results, found in the semi-structured interviews, are widely supported by the total study population of older patients in the Jeroen Bosch Hospital. In order to make sure that the perspective of all older patients with polypharmacy are taken into account, the criteria for including participants in the survey questionnaire will be lowered to patients of 65 years or older (instead of the initial 75 years or older). In addition, polypharmacy will be lowered to chronically using five or more different medications, instead of seven or more medications as was used in this research. The other in- and exclusion criteria remain identical to those included in this study.

Since the future research will comprise of a quantitative study, this provides the opportunity to further investigate possible associations between gender, educational level and the patient's role. With only ten interviews it is difficult to indicate interrelations between these factors, whereas this should be more feasible with a larger study sample. Furthermore, since only Dutch-speaking participants were included in the interviews it would be interesting to conduct a research on the perspectives of non-Dutch speaking patients and their views on medication safety in the hospital. Since non-Dutch speaking patients have a higher risk of miscommunication, this increases their chances on medication errors making them an important group to involve in future research.

Last, the findings of this study have shown that in order to improve patient participation, the role of HCPs is crucial. Therefore, more research should be done to explore ways in which HCPs can support and encourage older patients to be involved in their own medication. Simultaneously, possible barriers for HCPs in improving patient participation have to be identified and strategies have to be thought of in order to tackle these barriers and move forward towards patient-centered care.



## 7. Conclusion

This study investigated the view of older patients with polypharmacy on their role in in-hospital medication safety. Patients want to be informed about important aspects of their medication concerning new or changed medication. Patients prefer a clear and transparent communication. Furthermore, a division in patient roles is suggested in which three roles are being differentiated: i) passive, ii) active and iii) intermediate. Findings of this study seem to imply that the patient's role is linked to multiple factors, including educational level and gender. Actual health status, length of- and experience with disease(s) are thought to be possible influencers as well. The present study emphasizes the differences in needs and wishes of each patient concerning their role in medication safety. In order to let patients make a deliberate choice which role to occupy, being informed about medication is a primary step on the ladder of participation. A valuable collaboration between patient and healthcare professional is essential to move on the continuum of patient participation, with the ultimate, mutual goal being less medication errors and an improved medication safety.

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## Appendix A: PROPES-study invitation form



### Studie medicatieveiligheid

#### Uitnodiging patiënten voor een interview

*PAR-assisted Reduction of Prescribing Errors in Secondary care (PROPES)*

Geachte heer/mevrouw,

Met deze brief willen we u graag informeren betreffende een studie over medicatieveiligheid en u uitnodigen voor een eenmalig interview.

Ziekenhuisopnames leiden vaak tot een grote hoeveelheid aan medicatie voorschriften. Om de medicatieveiligheid in het Jeroen Bosch Ziekenhuis verder te verbeteren zal er een kwaliteitsverbeterproject van start gaan.

#### **Doel van het onderzoek**

Het PROPES-onderzoek heeft als doel het reduceren van fouten in voorgeschreven medicatie in het ziekenhuis. Wij denken dat patiënten een waardevolle rol kunnen vervullen in dit verbeterproject. Patiënten kunnen ons van informatie voorzien die ons kan helpen om effectievere verbeteracties te ontwikkelen. Daarnaast willen we inzicht krijgen in de mening van patiënten over het voorschrijfproces: Wat vindt u belangrijk bij het voorschrijven? Hoe wilt u betrokken worden bij het vaststellen welke medicatie er wordt gebruikt bij opname en bij eventuele medicatiewijzigingen tijdens opname? Wat gaat er goed en wat kan er beter?

#### **Wat betekent het als ik deelneem in dit project?**

Wij zouden u willen vragen om mee te doen aan een eenmalig interview. Als u toestemming geeft voor deelname zal iemand van het onderzoeksteam contact met u opnemen voor verdere informatie.

Het interview zal na ontslag plaatsvinden en wordt naar uw wens bij u thuis of in het ziekenhuis afgenomen. Het interview zal naar verwachting maximaal een uur duren. Deelname aan dit onderzoek is geheel vrijwillig. Mocht u zich tijdens het onderzoek bedenken over uw deelname, dan kunt u op ieder moment stoppen. Door deel te nemen aan dit onderzoek levert u een belangrijke bijdrage aan wetenschappelijk onderzoek. De resultaten van dit onderzoek bieden handvatten waarmee medicatieveiligheid in het ziekenhuis kan worden verbeterd en waarbij er wordt ingespeeld op de wensen en behoeften van de patiënt.

#### **Verwerking van gegevens**

Van het interview zal een audio-opname worden gemaakt. Deze zal na documentatie worden vernietigd. De gegevens zullen anoniem worden verwerkt en opgeslagen. De resultaten van het onderzoek worden gepubliceerd in medische tijdschriften, maar zullen nooit herleidbaar zijn naar u als persoon.



Mochten er naar aanleiding van deze informatie vragen of onduidelijkheden zijn dan kunt u contact opnemen met ondergetekende, bereikbaar op 06-57844708 of via [i.v.kessel@jbz.nl](mailto:i.v.kessel@jbz.nl).

Alvast bedankt voor uw medewerking.  
Met vriendelijke groet,

Isabelle van Kessel  
Masterstudente Gezondheidswetenschappen  
(e-mail: [i.v.kessel@jbz.nl](mailto:i.v.kessel@jbz.nl))  
(tel: 06-57844708)

Mede namens,

Prof. Dr. R. J. van Marum, klinisch geriater, klinisch farmacoloog - [r.v.marum@jbz.nl](mailto:r.v.marum@jbz.nl)  
Afdeling Geriatrie, postbus 90153, 5200ME 's-Hertogenbosch

Drs. E. van Kleef, arts-onderzoeker – [el.v.kleef@jbz.nl](mailto:el.v.kleef@jbz.nl)  
Dr. K. Smulders, senior adviseur Kwaliteit en Veiligheid – [k.smulders@jbz.nl](mailto:k.smulders@jbz.nl)  
Dr. H.J. Derijks, ziekenhuisapotheker, klinisch farmacoloog – [j.derijks@zanob.nl](mailto:j.derijks@zanob.nl)

**Klachten:** Als u zich zorgen maakt over enig aspect van dit onderzoek, neemt u dan contact op met iemand van het onderzoeksteam. Als uw zorgen niet zijn weggenomen, dan kunt u uw klacht telefonisch voorleggen aan een van de klachtenfunctionarissen van het Jeroen Bosch Ziekenhuis via 073-5532639. U kunt ook een e-mail sturen aan [klachtenfunctionarissen@jbz.nl](mailto:klachtenfunctionarissen@jbz.nl) of gebruik maken van het online klachtenformulier, te vinden via <https://www.jeroenboschziekenhuis.nl/Publicaties/109713/Patienten-Klachten>.

Om te bepalen of u in aanmerking komt voor deelname aan het onderzoek verzoeken wij u de volgende vragen te beantwoorden:

Ik ben 75 jaar of ouder:

- Ja                     Nee

Het aantal verschillende medicijnen die ik dagelijks gebruik:

- 0-4                     5-6                     7-9                     10 of meer

Hierbij verklaar ik dat ik toestemming geef dat een van de leden van het onderzoeksteam contact met mij opneemt voor een eenmalig interview.

Naam en voorletters:

Telefoonnummer:

E-mailadres:

Datum ondertekening:

Handtekening:

Bovenstaande persoonlijke gegevens worden uitsluitend gebruikt om u te benaderen voor deelname aan het interview. Na het interview zullen uw gegevens vernietigd worden.

*Voor algemene informatie over uw rechten bij verwerking van uw persoonsgegevens kunt u de website van de Autoriteit Persoonsgegevens raadplegen. Bij vragen of klachten over de verwerking van uw persoonsgegevens raden we u aan eerst contact op te nemen met de onderzoekslocatie. U kunt ook contact opnemen met de Functionaris voor de Gegevensbescherming van de instelling of de Autoriteit Persoonsgegevens. Functionaris voor de Gegevensbescherming van het Jeroen Bosch Ziekenhuis is bereikbaar per email via: [privacy@jbz.nl](mailto:privacy@jbz.nl)*

## Appendix B: Topic guide interviews

De vragen zijn gericht op het uitvragen van de **ervaringen, wensen en behoeften van de patiënt** (*Wat is uw ervaring, hoe zou u dit graag (anders) willen zien, hoe zouden wij u daarin (beter) kunnen ondersteunen?*)

### Algemene gegevens:

Leeftijd, hoogst genoten opleiding, afdeling, opnameduur, aantal medicamenten

### Laatste opname:

- Medicatieverificatie; gesprek met apothekersassistente
  - Veranderingen in medicatie
- Ervaringen, wensen, behoeftes
- Informatievoorziening
    - § *Soort informatie*
    - § *Manier van informatievoorziening*
    - § *Begrijpelijkheid van informatie*
    - § *Vragen over informatie*
  - Betrokkenheid bij beslissingen
    - § *Medicatie in eigen beheer*
    - § *Mate en manier van betrokkenheid*
    - § *Soort beslissingen*
    - § *Stimuleren van betrokkenheid*
    - § *Vermogen om mee te beslissen*
- Medicatiefouten (*Ging er wel eens iets mis met de medicatie?*):
- Ervaringen, wensen, behoeftes
- *Soort fout*
  - *Rol van ziekenhuis*
  - *Rol van patiënt*
- Situatieschets medicatiefout <sup>a</sup>
- *In kennis willen worden gesteld?*
  - *In hoeverre betrokken?*
  - *Gevoel bij fout*
  - *Schadelijke fout: informatie en betrokkenheid*
  - *Ondersteuning vanuit ziekenhuis*
  - *Rol van patiënt*

### Bij/na ontslag:

- Medicatieverificatie; gesprek met apothekersassistente
- Informatievoorziening: ervaringen, wensen, behoeftes
  - *Soort informatie*
  - *Manier van informatievoorziening*
  - *Begrijpelijkheid van informatie*
  - *Vragen over informatie (waar terecht?)*
  - *Overdracht thuisapotheek*
- Medicatiefouten: ervaringen, wensen, behoeftes
  - *Soort fout*
  - *Rol van ziekenhuis*
  - *Rol van patiënt*

<sup>a</sup> added during data collection

## Appendix C: Informed Consent

### Toestemmingsformulier PROPES-studie

*PAR-assisted Reduction of Prescribing Errors in Secondary care (PROPES)*

- Ik heb de informatiebrief gelezen. Ik ben mij bewust van het doel, de methode en verwerking van deze studie. Ik kon aanvullende vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen over deelname.
- Ik weet dat meedoen aan deze studie geheel vrijwillig is. Ik weet dat ik op ieder moment kan beslissen om toch niet mee te doen. Daarvoor hoef ik geen reden te geven.
- Ik weet dat sommige mensen mijn gegevens kunnen zien. Deze personen zijn vernoemd in de informatiebrief.
- Ik weet dat mijn gegevens anoniem worden verwerkt en nooit herleidbaar zijn tot mij als persoon.
- Ik geef toestemming om mijn gegevens te gebruiken voor de doelen die in de informatiebrief staan. De uitkomsten van dit interview mogen verwerkt worden in een wetenschappelijke publicatie.
- Ik geef toestemming om een audio-opname van het interview te maken.

Naam deelnemer:

Datum: \_\_ / \_\_ / \_\_

Handtekening:

.....

Onderzoeker:

Ik heb mondeling toelichting verstrekt over het doel, de methode en verwerking van de studie. Ik verklaar mij bereid nog opkomende vragen over het onderzoek naar vermogen te beantwoorden.

Naam onderzoeker:

Datum: \_\_ / \_\_ / \_\_

Handtekening:

.....

## Appendix D: Code vocabulary

### Demografische gegevens

- DG – geslacht
- DG – leeftijd
- DG – afdeling
- DG – opleiding
- DG – opnameduur
- DG – aantal verschillende med
- DG – med-manag thuis: Baxter-rol
- DG – med-manag thuis: zelfstandig mbv weekdoos
- DG – med-manag thuis: door partner mbv weekdoos
- DG – med-manag thuis: zelfstandig, dagelijkse organisatie van med.
- DG – kennis van eigen medicatie: ja
- DG – kennis van eigen medicatie: nee

### Medicatiemanagement ziekenhuis

- Med-manag – huidig: beheer door zh
- Med-manag – huidig: beheer door pt
- Med-manag – huidig: medicatie (deels) in eigen beheer
- Med-manag – gewenst: geen voorkeur
- Med-manag – gewenst: beheer door zh
- Med-manag – gewenst: beheer door pt
- Med-manag – gewenst: medicatie (deels) in eigen beheer
- Med-manag – gewenst: zh regelt med, pt controleert (actieve rol)
- Med-manag: per pt verschillend
- Med-manag: bekertje pillen, geen info
- Med-manag: bijwerkingen
- Med-manag: overname med fijn
- Med-manag: overname med vervelend
- Med-manag: overname zh geen keuze
- Med-manag: belang van eigen beheer med
- Med-manag: te ziek voor eigen beheer med
- Med-manag: vertrouwen in professionals

### Medicatieverificatie: opname

- Medver: geen gesprek
- Medver: geen herinnering van gesprek
- Medver: te ziek voor gesprek
- Medver: Baxter-rol meegebracht
- Medver: eigen medicatielijst meegebracht
- Medver: medicatie pt al bekend in zh
- Medver: gesprek arts met pt
- Medver: gesprek apothekersassistente met pt
- Medver: gesprek apothekersassistente met familie/partner

### Medicatiewijzigingen

Med-wijziging: geen idee  
Med-wijziging: ja  
Med-wijziging: nee  
Med-wijziging: andere toedieningswijze  
Med-wijziging: geïnformeerd  
Med-wijziging: niet geïnformeerd  
Med-wijziging: belang van informeren  
Med-wijziging: uitleg vragen  
Med-wijziging: geen uitleg vragen  
Med-wijziging: geen uitleg nodig  
Med-wijziging: vertrouwen op professionals  
Med-wijziging: preferentiebeleid – geen problemen mee

### **Informatie**

Info-vz – gekregen info: geen  
Info-vz – gekregen info: voldoende  
Info-vz – gekregen info: onvoldoende  
Info-vz – gemiste soort info  
Info-vz – gemiste soort info: reden voorschrift  
Info-vz – gemiste soort info: bijwerkingen  
Info-vz – gewenste soort info  
Info-vz – gekregen soort info  
Info-vz – duidelijk  
Info-vz soort – zh: mondeling  
Info-vz soort – zh: schriftelijk  
Info-vz soort – gewenst: mondeling  
Info-vz soort – gewenst: schriftelijk  
Info-vz soort – gewenst: gekwalificeerd persoon  
Info-vz: belangrijk  
Info-vz: fijn  
Info-vz: vertrouwen op professionals  
Info-vz: pt vergeet info  
Info-vz: pt zoekt zelf info op

### **Vragen**

Vragen stellen over med – ja  
Vragen stellen over med – ja: uitleg  
Vragen stellen over med – nee  
Vragen stellen over med – nee: uitleg

### **Betrokkenheid (beslissingen) medicatie**

Betrokkenheid – zh: geen herinnering  
Betrokkenheid – zh: pt voelt zich betrokken  
Betrokkenheid – zh: pt voelt zich niet betrokken  
Betrokkenheid – zh: vertrouwen in professionals  
Betrokkenheid – gewenst: betrokken  
Betrokkenheid – gewenst: niet betrokken  
Betrokkenheid – uitleg: geen kennis  
Betrokkenheid – uitleg: noodzaak innemen medicatie  
Betrokkenheid – uitleg: verbetering gezondheid als maatstaf

Betrokkenheid – gestimuleerd door personeel: ja  
Betrokkenheid – gestimuleerd door personeel: nee

### **Shared-decision making**

Shared-decision – geen voorkeur  
Shared-decision – voorkeur  
Shared-decision – geen voorkeur: uitleg  
Shared-decision – voorkeur: uitleg

### **Rol patiënt**

Rol pt – actief  
Rol pt – passief  
Rol pt – moeilijk om controle uit handen te geven  
Rol pt – afhankelijk van gezondheid  
Rol pt – monitoren van gezondheid  
Rol pt – waarden vergelijken thuis vs. zh  
Rol pt – bijsluiter lezen  
Rol pt – gekregen medicatie controleren  
Rol pt – vpk herinneren aan geven med  
Rol pt – kennis en ervaring eigen med  
Rol pt – ongemakken aangeven  
Rol pt – ongemakken niet aangeven  
Rol pt – online informatie zoeken  
Rol pt – begrip voor fouten  
Rol pt – vervelend gevoel door actieve houding  
Rol pt – gewenst: meer informatie vragen  
Rol pt – gewenst: actieve rol in voorkomen med-fout, controlefunctie

### **Rol ziekenhuis**

Rol zh – bejegening door professional  
Rol zh – pt voelt zich niet gehoord door professional  
Rol zh – pt voelt zich gehoord door professional  
Rol zh – continuïteit van artsen  
Rol zh – reageren op vragen/zorgen pt  
Rol zh – vpk noteert opmerkingen pt  
Rol zh – acceptatie professional shared-decision making  
Rol zh – gewenst: acties communiceren  
Rol zh – gewenst: luisteren naar pt  
Rol zh – gewenst: klachten pt serieus nemen  
Rol zh – gewenst: persoonlijk contact met professional  
Rol zh – gewenst: pt voorzien van informatie  
Rol zh – gewenst: pt voorzien van goede nazorg  
Rol zh – gewenst: regelmaat in pt voorzien van med

### **Medicatiefout**

Med-fout thuis: ja  
Med-fout thuis: nee  
Med-fout zh: ja  
Med-fout zh: nee  
Med-fout voorbeeld 1

Med-fout voorbeeld 2  
Med-fout voorbeeld 3  
Med-fout: betrokken  
Med-fout: niet betrokken  
Med-fout: uitleg niet betrokken  
Med-fout: actieve rol pt  
Med-fout: actieve rol pt – verandering signaleren  
Med-fout: actieve rol pt – navraag doen bij vpk  
Med-fout: actieve rol pt – noodzakelijk  
Med-fout: passieve rol pt  
Med-fout: begrip voor fouten  
Med-fout: zh kan het beter doen  
Med-fout: betrokkenheid van familie  
Med-fout: voorkeur voor informeren  
Med-fout: voorkeur voor niet informeren  
Med-gevoel zh: veilig  
Med-gevoel zh: onveilig  
Med-gevoel zh – fout: vervelend  
Med-gevoel zh – fout: ongerust  
Med-gevoel zh – fout: niet ongerust

**Medicatieverificatie: ontslag**

Ontslag – medver: geen  
Ontslag – medver: geen herinnering van gesprek  
Ontslag – medver: gesprek arts met pt  
Ontslag – medver: gesprek apothekersassistente met pt  
Ontslag – medver: gesprek apothekersassistente met familie/partner  
Ontslag – medver: duidelijke info  
Ontslag – medver: gemiste info  
Ontslag: helder contactpunt voor vragen  
Ontslag: medicatie niet in voorraad