Summary
Introduction and research questions

Medical practice variation is a well-known phenomenon that has been extensively described in the literature [e.g. 1-3]. Variation in medical treatment means that similar, or apparently similar patients with a similar health status or medical condition do not receive the same treatment. Variation is explained in current research by focussing mainly on physicians and the organisations they work in [4]. This approach might be adequate in cases where physicians are the dominant actor deciding on the treatment. In the past decades, however, this paternalistic model has become questioned. In parallel, there is an increased emphasis towards including patients and their preferences in medical decision-making [5, 6]. Moreover, providing care that is respectful of, and responsive to, an individual patient's preferences is regarded as one aspect of a good quality of care [7]. Since medical decision-making is a decisive factor for practice variation, this raises the question whether patients can be ignored in theories about variation. This question was the central subject of this thesis. In order to gain insight into this subject, we examined under which circumstances the interaction between physician and patient is not dominated by the physician. We explored several mechanisms explaining patient involvement in medical decision-making. We examined, too, how this involvement influences medical decision-making, and thus practice variation. It has been suggested that patient involvement, and more specifically shared decision-making (SDM), decreases variation [8-12]. However, empirical data showing this was lacking.

The two research questions addressed in this thesis were:

1. Which mechanisms explain differences in patient involvement in medical decision-making?

2. How does patient involvement, and more specifically shared decision-making, influence medical practice variation?

In line with our two research questions, this thesis is divided into two parts. Part A aims to achieve insight into three possible mechanisms which might explain patient involvement in medical decision-making, and comprises the Chapters 2 to 4. Part B, Chapters 5 and 6, seeks to achieve insight into how patient involvement, and more specifically SDM, influences medical practice variation.
Mechanisms explaining differences in patient involvement in medical decision-making

We examined under which circumstances the physician-patient interaction is not dominated by the physician. It is only if patients share medical decision-making with their physician that they should be modelled as actors in theories about variation. Previous studies have shown that there is variation in patient involvement in medical decision-making [e.g. 13]. However, no clear explanation for this observed variation has been given. We therefore examined three mechanisms, both at the micro (patient) and the meso level (social context) which may explain patient involvement in medical decision-making. These were: 1) health literacy, 2) social support and, 3) social norms.

Chapter 2 examined the relationship between health literacy and self-reported involvement in medical decision-making. Health literacy refers to “personal characteristics and social resources needed for people to access, understand and use information to make decisions about their health” [14 p2, 15 p1]. We hypothesised that people with higher health literacy report that they are more involved in medical decision-making. This, we presume, is because these people are able to obtain, understand, appraise, and apply information required for medical decision-making better. A structured questionnaire was sent to members of NIVEL’s Dutch Health Care Consumer Panel in May 2015 (response 46%, N=974). Health literacy was measured using five scales of the Health Literacy Questionnaire [16]. A regression model was used to estimate the relationship between health literacy and self-reported involvement. In general, our results did not show a relationship between health literacy and self-reported involvement. However, we found that the higher respondents scored on the health literacy scale ‘appraisal of health information’, the more they reported being involved in medical decision-making. As such, our hypothesis was partly confirmed. Our findings suggest that higher order competences, that is to say ‘critical’ health literacy, in particular, are important in reporting involvement in medical decision-making. ‘Information appraisal’ is one component of critical health literacy. This refers to cognitive skills in managing and interpreting information, as well as to assessing the personal relevance of information [17]. In the context of this thesis, it appears that in order to be involved in medical decision-making, patients have to be able to interpret information and weigh this information against their own preferences.
Chapter 3 studied the role of social support, in the form of the availability of informational and emotional support, on the attitude that people have towards taking an active role in medical decision-making. One reason for patients to leave medical decision-making to their physician is the information asymmetry between them and the physician [18]. Patients believe that medical decision-making requires knowledge they do not have [19]. We hypothesised that gaining informational support from others may compensate for this lack of knowledge. Another reason to leave decision-making to the physician is that people who are sick feel vulnerable and thus do not want to, or cannot, take a decision [20, 21]. We hypothesised that emotional support, in the form of having someone to take with you to a medical consultation, can compensate for this. Patients are expected to feel less vulnerable if they receive emotional support as it has been suggested that they feel more confident when a companion is present [22]. A questionnaire was sent to members of NIVEL’s Dutch Health Care Consumer Panel (response 70%, N=1,300) in June 2013. A regression model was then used to estimate the relationship between medical and lay informational support and emotional support, on the one hand, and attitudes towards taking an active role in medical decision-making on the other. We found that people to whom more medical informational support is available, that is knowing people who are medical professionals, are more positive towards taking an active role in medical decision-making. The reason for this might be that they are able to contact someone who is a medical professional within their network more easily and thus seek medical information necessary for decision-making. On the other hand, we found no relationship between the availability of lay informational support, that is having lay people in your network to seek information from, and taking an active role in decision-making. We also found that it was only in people with a low level of education that the availability of emotional support related positively to their attitude towards taking an active role in medical decision-making. This is not the case in people with a middle or high level of education. The latter have a more positive attitude towards taking an active role in medical decision-making, irrespective of the level of emotional support available. In conclusion, our findings showed that social support does play a role in patient involvement. However, not all forms of support play a role in all groups of patients. As such, our hypothesis was partly confirmed.

Chapter 4 provided insight into how social norms play a role in self-reported involvement in medical decision-making. Social norms define what actions are
regarded as normal by a group of people, and what actions are regarded as deviant [23]. We made a distinction between subjective norms, that is doing what others think one ought to do, and descriptive norms, that is doing what others do [24]. We hypothesised that for both norms, the more it is common in someone’s social context to leave the decision to a physician then the less someone reports being involved in medical decision-making. The reason for this is that we expected that people will behave according to the norms of their social environment, as this will result in social approval. A questionnaire was sent to members of NIVEL’s Dutch Health Care Consumer Panel in May 2015 (response 46%; N= 974). A regression model was used to estimate the relationship between social norms and involvement in medical decision-making. Our results confirmed our hypothesis. With regards to the subjective norm, we found that the more a person thinks that, according to significant others, he or she has to leave the decision to the physician, the less that person reports being involved in the decision-making process. The same was found for the descriptive norm. The more people think that significant others leave the decision to the physician, the less they report being involved in the decision-making process.

In conclusion, the results of the Chapters 2, 3 and 4 show that the mechanisms of health literacy, social support, and social norms are all three associated with patient involvement in medical decision-making. Our results suggest that, in general, high critical health literacy, the availability of medical informational support, and non-conservative social norms are positively related to patient involvement in medical decision-making. As such, patients have to be modelled as actors in theories about variation. Our findings also suggest that the decision to be involved in medical decision-making is not as individual as it first would appear. A person’s social context also plays a role.

Patient involvement and medical practice variation

Treatment decisions may change as a result of patient involvement in medical decision-making. The reason for this is that patients’ preferences for treatment may differ from physicians’ judgements [25]. Medical decision-making is decisive for variation, therefore patterns of variation may also change through patient involvement. It has been hypothesised that patient involvement, and more specifically SDM, decreases variation in practice [8-12]. However, empirical data
confirming a decrease was lacking. We aimed, therefore, to examine how patient involvement, and more specifically SDM, influences medical practice variation.

In Chapter 5, we tested, empirically, the hypothesis that SDM reduces medical practice variation. We hypothesised that SDM is associated with less variation between units such as hospitals, as we expected that, due to SDM, a more conservative treatment option will be chosen in units where physicians already prefer the more conservative option, as well as in units where physicians prefer the invasive option. This is because informed patients prefer the more conservative option. Based on a limited data set, we examined how SDM is associated with variation in the choice of single embryo transfer (SET) or double embryo transfer (DET) after in vitro fertilisation. We examined variation between and within hospitals. We found a large degree of variation in the choice of SET or DET between hospitals in the control group, while less variation was found between hospitals in the group with a strategy to promote SDM. As such, our hypothesis was confirmed. In addition to this, we found that within most hospitals the variation in the choice of SET or DET appeared to increase due to a strategy to promote SDM. While in other hospitals the variation in the choice of SET or DET decreased, or remained equal. An implication of our results is that an overall decrease in variation between hospitals gives no indication about the change in variation within an individual hospital.

Chapter 6 provided insight into the possible conflict between applying guidelines on the one hand, and including patient preferences in medical decision-making on the other. We examined whether patient preferences have a role in the prescribing of antibiotics in general practice and how this affects adherence to guidelines. We hypothesised that preferences play a larger role in prescribing antibiotics if the guideline allows for preferences to be taken into account. In other words if prescribing antibiotics is an option which can be considered rather than a clear recommendation to prescribe or not. We included three guidelines: acute cough, acute rhinosinusitis, and urinary tract infections. Data from the NIVEL Primary Care Database (NIVEL-PCD) were used to assess antibiotic indications and prescriptions. These data were combined with a questionnaire among members of NIVEL’s Dutch Health Care Consumer Panel to examine the patient’s preferences. According to NIVEL-PCD, 286 of these members contacted their general practitioner (GP) in 2015 for acute cough, acute rhinosinusitis or urinary tract infections. A logistic multilevel regression analysis was performed to test our hypothesis. We found that patient
preferences appear only to play a role in the GP’s prescribing of antibiotics if prescribing an antibiotic was an option that could be considered (interaction between indication and preference: p=0.049). If patients ask for antibiotics themselves in such situations then GPs prescribe antibiotics more often. In those situations there is no conflict between applying the guidelines and including the patient’s preferences. Antibiotics are justified in such situations as the guideline provides room for taking patient preferences into account. As such, our hypothesis was confirmed.

In conclusion, the results of the Chapters 5 and 6 show that patients taking an active role in the decision-making process influence the decision taken and thus the variation.

**Conclusions**

In conclusion, this thesis was the first to include the physician-patient interaction in testing a theoretical model explaining medical practice variation. We aimed to gain insight into under which circumstances the physician-patient interaction is not dominated by the physician, and if this is the case, how patient involvement influences the decision taken, and thus practice variation. We found that health literacy, social support, and social norms are all three mechanisms associated with patient involvement in medical decision-making. Our results suggest that, in general, high critical health literacy, the availability of medical informational support, and non-conservative social norms are positively related to patient involvement in medical decision-making. As such, patients have to be modelled as actors in theories about variation. An implication of our results is that the decision to be involved in medical decision-making is not as individual as it first seems. A person’s social context also plays a role. This thesis also proved that patient involvement in medical decision-making influences the decision taken, and thus practice variation. We found that SDM results in less variation between hospitals. As such, we confirmed, empirically, the hypothesis from the literature that SDM reduces medical practice variation. Until now empirical data showing such a decrease was lacking. In addition, we found that SDM results in another pattern of variation within hospitals. An implication of our results is that an overall decrease in variation between hospitals gives no indication about the change in variation within an individual hospital. Lastly, we found that two mechanisms – guidelines
and patient involvement – which both have the potential to reduce practice variation, do not conflict each other. Our results suggest that patient preferences only play a role if the guideline provides room to take preferences into account. In conclusion, our model proved to be valuable in order to gain insight into circumstances under which the physician-patient interaction is not dominated by the physician. If this is the case then insight is also gained into how this influences the decision taken, and thus practice variation. We believe this thesis provides sufficient insight to argue that, under certain circumstances, patients cannot be ignored in theories about variation. However, some questions remain unanswered. Therefore, several recommendations for future research have been made.