Valorisation
As defined by the Maastricht Valorisation Centre, “valorisation is the process of creating value from knowledge, by making this knowledge available and suitable for economic and social exploitation and to translate this knowledge into products, services, processes and new business” [1]. Valorisation also relates to making the findings of scientific research available, or more easily available, to enhance the chances that other stakeholders outside the academic world will make use of it. It is also about making knowledge in co-production with non-academic stakeholders [2]. In this valorisation section, we will describe how the findings of this thesis can be of value outside the academic world. More specific, we discuss valorisation in the context of patient involvement in medical decision-making and in the context of patient involvement and medical practice variation. Furthermore, activities that have been done to disseminate our findings to others, both inside and outside the academic world, are presented. We also describe how non-academic stakeholders were involved in the studies performed in this thesis.

In this thesis, we tested a theoretical model and as a result we gained knowledge about the role of patients in theories about variation in medical practice. First, we found that the decision to be involved in the decision-making process is not that individual as it at first seems. This conclusion is based on our findings that suggest that both social support and social norms play a role in the decision to take an active role in medical decision-making. We also found that critical health literacy plays a role in this decision. Second, we found that if patients are involved in the decision-making process this influences the decision taken and thus the variation. This observation is based on our findings that shared decision-making (SDM) results in less variation between hospitals, and another pattern of variation within hospitals. Furthermore, we found that two mechanisms, guidelines and patient involvement, that are both able to reduce practice variation, do not have to conflict with each other. Valorisation was part of this thesis as will be explained below.

**Patient involvement in medical decision-making**

Part A of this thesis showed under which circumstances patients take an active role within medical decision-making. In 2006, the Netherlands introduced a new health insurance system based on managed competition. The introduction of this system was, among others, intended to force a shift from supply to demand driven care: the demand and needs of patients should be leading in the provision of care [3].
This implies that, at an individual level, patients have to take up an active role in decisions about their health. Not only in the Netherlands, also in other countries, patient involvement is on the agenda of policy makers, professional bodies, patient representatives groups, and health insurers [4, 5]. Our findings are therefore not only relevant for policy and practice in the Netherlands, but also for other countries that aim to emphasise patient involvement in decision-making. It has been argued that there is a strong patient participation movement at both the macro and meso level in the Netherlands. However, at the micro level, or in daily practice, there is room for improvement [5]. Findings of this thesis provide directions for addressing this improvement and therefore producing social value of our results. SDM is found to be positively related to patient outcomes, such as improved satisfaction and less decisional conflict [6]. Through this thesis, we have provided insight into three mechanisms that play a role in whether patients take an active role in decisions about their health. We found that the decision to be involved is not that individual as it at first seems. Our findings provide some directions to improve patient involvement in daily practice, however, it has to be recognised that there always will be a group of patients that is not able or not willing to take an active role in medical decision-making.

Our findings confirm that people do not make decisions in a ‘vacuum’ even in the context of SDM. Strategies aimed at emphasising SDM within daily practice have to address this social context too. To inform the Ministry of Health, Welfare and Sport about this, we presented our results to several delegates of the Ministry of Health, Welfare and Sport in October 2017. Next to the results, we presented several directions for policy. For example, supported by our finding that for low educated people taking someone with you to a medical consultation is positively related to involvement, patients can be more actively stimulated to take someone with them to the medical consultation when decisions about their health have to be taken. Afterwards, there was a discussion with the attendees about the role that the context of people might play in decisions they make. In the near future, we aim to present our results to other stakeholders, for example by giving a presentation during a meeting of the program committee of the Dutch Health Care Consumer Panel. Within this committee several stakeholders are represented.

Although our findings provide some directions to improve patient involvement in daily practice, the mechanisms examined in this thesis did not explain all variation in whether patients take an active role in medical decision-making. Therefore, we
provided some directions for future research in the Discussion of this thesis. Efforts have already been made to examine several of these directions for future research. In 2018, we start with unravelling the relation between trust and patient activation (i.e. having the knowledge, skills, confidence, and behaviours needed for managing one’s own health and health care [7]) on the one hand, and patient involvement on the other. In addition, for the Dutch Ministry of Health, Welfare and Sport, patient involvement is an important topic. Besides the data used for this thesis, also other data about this subject have been collected in the Dutch Health Care Consumer Panel. Since 2016, the Ministry have asked us to measure levels of SDM, using the SDMQ-9 [8], among the Dutch population aged 18 years and older. Moreover, we measure since 2016 the extent to which patients find that their general practitioner involves them in decisions about their treatments (88% answered mostly or always, in 2016). This percentage is shown as key figure on the website of ‘De Staat van Volksgezondheid en Zorg’ (Staat van VenZ) [9]. The goal of this Staat van VenZ is to present actual and unambiguous key figures to monitor and to account for the policy of the Dutch Ministry of Health, Welfare and Sport [10]. Furthermore, we presented our results in two one page factsheets [11, 12], which were sent to, among others, the Ministry of Health, Welfare and Sport. These factsheets were highly appreciated in the field. Finally, the data collected can be used in the future to examine new research questions about this subject, and to examine whether patient involvement has been improved in daily practice.

Patient involvement and medical practice variation

Compared to our results regarding patient involvement in medical decision-making, valorisation of our results about the role of patient involvement in explaining medical practice variation is more complex. Part B of this thesis shows that if patients are involved in medical decision-making this is of influence on the decision taken, and therefore on variation. Although there is increased attention for patient involvement in decision-making, the question of how this is of influence on practice variation is a rather new one in the field. Before this thesis, no clear theoretically derived hypotheses were available. Furthermore, empirical data confirming that patient involvement, and more specifically SDM, reduces practice variation was lacking. We tried to close this gap in the knowledge by formulating several hypotheses and by empirically testing the hypothesis that SDM reduces practice variation. By including patients as an actor in theories about practice variation, we
diverged from current research that explains variation by focusing mainly on physicians and the organisations they work in.

Our results show that if patients are involved in medical decision-making this is of influence on the decision taken, and thus on variation. However, a limitation is that both studies in part B of this thesis are based on limited data sets, each focusing on just one decision-making situation. An important question is to what extent our results are applicable to other decision-making situations. Nevertheless, our findings are important to consider for several stakeholders. As argued, practice variation is in itself not a bad thing, as without variation there might not be any advancement in health care [13]. However, the problem is that it is not clear what is behind practice variation as physicians are not able to clarify why there is such variation. For policy makers and health insurance companies, practice variation is a sign of physicians using unnecessary treatments, and thus a sign of unnecessary spending [13]. Our observation that SDM reduces practice variation between hospitals might provide new insights for policy makers and insurance companies about this subject. If they aim to decrease variation, it might be a possibility to focus on the involvement of patients instead of on the behaviour of physicians only. However, policy makers and insurance companies have to be aware that SDM might increase variation within an individual hospital.

For researchers, our findings provide directions for further research about theories on practice variation. Next to testing whether our results are applicable to other decision-making situations, it is recommended to further elaborate upon possible hypotheses about the role of patients in theories about variation. Regarding this, we are now examining to what extent SDM is associated with inappropriate antibiotics prescription rates in general practice. We hypothesise that rates of inappropriate antibiotics prescription are lower in general practices where SDM takes more often place. To test this we make use of a combined set of data of the NIVE Primary Care Database and NIVE’s Dutch Health Care Consumer Panel.

**Dissemination**

To disseminate our results inside and outside the academic world several activities have been employed. These activities are explained hereafter. We also explain how we involved non-academic stakeholders in the studies performed.
First, the scientific results that are presented in the Chapters 2 to 6 are published in five different international peer-reviewed journals. Most of these journals are open access journals, which means that the articles are available for the public freely and without any restrictions. Some of these articles have already been cited by authors of other scientific articles. Moreover, our study published in 2016 in the BMJ Open (see Chapter 5) is referred to in a blog of ‘Innovations in Healthcare’, being a non-profit organisation hosted by Duke University [14].

Second, we presented our findings at three international conferences. These were: 1) the Wennberg International Collaborative (London, September 2015), 2) the European Public Health Conference (Milan, October 2015), and 3) the European Public Health Conference (Stockholm, November 2017). At the European Public Health Conference of 2015, an abstract of the study presented in Chapter 3 was nominated for the Ferenc Bojan Young investigator award.

Third, we have disseminated our findings to relevant stakeholders outside the academic world. The Dutch Health Care Consumer Panel has a program committee. This committee consists of representatives of the following stakeholders in the healthcare sector: the Dutch Ministry of Health, Welfare and Sport, the Association of Health Care Insurers in the Netherlands, the National Health Care Institute, the Dutch Healthcare Authority, the Federation of Patients in the Netherlands, the Dutch Health Care Inspectorate and the Dutch Consumers Association. All the publications that are based on data collected within the Consumer Panel are sent to the members of the program committee to inform them about the results and to give them the possibility to distribute the results to relevant persons within their organisation. In this thesis, the Chapters 2, 3, 4 and 6 are based, or partly based, on data collected within the Consumer Panel, and as such sent to the members of the committee.

The members of this program committee were also involved in the development of the questionnaires used in the studies of the Chapters 2, 3, 4 and 6. We send all the draft questionnaires to the members of the committee to give them an opportunity to comment on the draft questionnaire. Based on the comments of the committee, we were able to improve our questionnaires, and to make sure that these are more in line with practice.
The study of Chapter 6 is partly based on research performed in the cooperative framework that NIVEL and The National Health Care Institute had. During this research an employee of the Health Care Institute was seconded at NIVEL for one day a week to work together with NIVEL researchers on the research about the role of patients in non-adherence to antibiotic guidelines by general practitioners. Both NIVEL and the Health Care Institute published a news item on their website to pay attention to the report that has been published about this research. This news item was taken over by several others, like the Nationale Zorggids [15] and Skipr. We also disseminated the results to general practitioners by publishing a short summary of the report in Huisarts en Wetenschap [16], the official journal of the College of General Practitioners.

Finally, to stay informed about other research and to stay in contact with other researchers in the field of medical practice variation, the author of this thesis is member of the Wennberg International Collaborative (WIC). The WIC aims to “accelerate research into the causes and consequences of unwarranted health care variation across regions and providers” [17]. Both researchers and policy makers are members of the WIC [17].