Summary
**Introduction**

In the Netherlands, citizens are expected to fulfill an autonomous and responsible role when it comes to their health and healthcare. This is induced by various social developments, such as: legal reforms to strengthen the patient’s position, more attention for patient-centred care, pressure on the healthcare system due to an aging population, and reforms to transform the Dutch healthcare system from supply regulated to demands regulated. The focus on individual responsibility with respect to health and care, places an increased emphasis on peoples’ health literacy skills. Health literacy can be defined as an individual’s skills to access, understand, appraise and apply health related information. In contemporary society, people with higher health literacy skills may be advanced over those who have lower health literacy skills, when it comes to health. Several studies show an association between lower health literacy and adverse health-related outcomes, such as a poorer ability to follow medical instructions, more hospitalizations, less use of preventive care and a lower level of self-care. Thus, health literacy seems an important determinant of public health. However, health literacy is a relative new concept and most studies on the determinants of health literacy, allied psychological processes and health-related consequences have been performed in the USA. Therefore, the research in this thesis aimed to obtain insight into the health literacy skills of Dutch adult in relation to socio-economic and demographic characteristics, psychological factors, health actions and health. Health actions refer to healthcare access and use, management of health and illness and patient-provider interaction. Particularly with respect to chronic care and prevention (i.e., screening and vaccination), an increased attempt is being made to individuals’ responsibility. Therefore it is especially relevant to study the role of health literacy in these areas.

**Health literacy in the Dutch adult population**

In the first part of this thesis two studies were described that aimed to explore to what extent health literacy among Dutch adults related to socio-economic and demographic characteristics and to perceived health. This was in the first place done based on data that was obtained in the 2012 European Health Literacy Survey (HLS-EU) (Chapter 2). The instrument that was developed and used in the HLS-EU to measure health literacy, measured perceived difficulties with accessing, understanding, appraising and applying health-related information over three domains: healthcare, disease prevention and health promotion. Given the range from 1 (the lowest score) to 4 mean scores ranged from 3.1 for appraising information to 3.4 for understanding information across all domains.
However, perceived difficulties varied to some extent per health domain. For instance, accessing information was perceived as more difficult in the healthcare domain (mean 2.6) than in the disease prevention domain (mean 3.4). Individuals with a lower level of education and a lower perceived social status perceived more difficulties with all four skills than those who had a higher education and a higher perceived social status. In addition, males perceived more difficulties than females with all four skills. Furthermore, age was negatively associated with accessing and understanding health-related information, but was not associated with appraising and applying health-related information. The results of this study imply that perceived difficulty with health-related information may differ according to the type of health literacy skill and the context in which health literacy skills are addressed. In addition, associations with socio-economic and demographic characteristics vary according to the type of skill and domain.

A second study examined whether health literacy constitutes a pathway in the association between education on the one side and perceived general health, perceived physical health and perceived mental health on the other (Chapter 3). For this purpose, data from the 2008 Adult Literacy and Life Skills Survey (ALL), including the Health Activities and Literacy Scale (HALS) were used. In contrast to the HLS-EU, in which health literacy is operationalized as perceived difficulties with health-related information, the HALS operationalizes health literacy as the score on a set of reading and problem-solving tasks. Based on this operationalization, in this study, lower health literacy was associated with the person’s level of education; those with a higher education showed higher health literacy scores.

Furthermore, it was found that those with lower health literacy reported worse self-reported general, physical and mental health than those with higher health literacy. Having completed a lower level of education was also associated with lower perceived general, physical and mental health. Mediation analyses indicated that health literacy mediated the association between education and self-reported general, physical and mental health. This finding indicated that part of the association between lower level of education and lower perceived health could be attributed to lower health literacy. Based on both studies, it could be concluded that lower health literacy is more often prevalent among those who have attained a lower level of education, have a lower perceived social status, or who are elderly or male. Subsequently, health literacy provides a contribution to explaining education-related variation in perceived health.
Health literacy in the context of chronic care

The aim of the second part of this thesis was to obtain insight into the extent to which health literacy is associated with (psychological determinants of) the use of primary care, patient-provider interaction and self-management in the context of chronic care. Firstly, it was examined to what extent health literacy relates to indicators of diabetes self-management and whether diabetes knowledge constitutes a pathway between health literacy and diabetes self-management indicators (Chapter 4). This study included a secondary data analysis based on a cross-sectional sample of patients with predominantly type 2 diabetes obtained from patient registrations and questionnaires completed in 2010. Perceived health literacy was assessed using the Set of Brief Screening Questions (SBSQ). The study showed that lower health literacy was associated with a higher HbA1c level, less physical activity and lower odds for performing self-control of glucose levels than those with higher health literacy. No significant association was found between health literacy and self-reported monitoring of glucose levels or between health literacy and smoking. With respect to the association between diabetes knowledge and self-management indicators, the study showed that patients with more knowledge were more likely to control their glucose levels themselves and less likely to smoke, compared to patients with less knowledge. No association was found between diabetes knowledge and the other indicators. Finally, diabetes knowledge mediated the association between health literacy and glucose self-control and between health literacy and smoking.

The results of this study indicate that the association between health literacy and self-management is not straightforward and depends on the type of self-management behaviour. The results also imply that knowledge is more important for certain self-management tasks than for others; therefore, efforts to increase diabetes knowledge may not always lead to better outcomes among those with lower health literacy. Knowledge as well as health literacy skills seem to be important for self-management. Interventions directed at increasing both are expected to have a positive effect on more aspects of self-management than interventions directed at enhancing only knowledge or health literacy skills.

In another study, it was examined to what extent health literacy relates to perceived control over care and the frequency of GP visits (Chapter 5). This study was based on a sample of chronically ill and disabled adults. Thereby, a distinction was made between functional, communicative/interactive and critical health literacy as assessed by the Functional, Communicative, Critical Health Literacy scale (FCCHL). Functional health literacy refers to basic literacy skills. Communicative or interactive health literacy refers to the more advanced
(cognitive and social) skills needed to obtain and apply health-related information. Critical health literacy refers to even more advanced (cognitive and social) skills that are needed to critically analyse information. Perceived control over care was indicated by perceived ability to organize care, interact with healthcare providers and perform self-care. After controlling for various patient characteristics, interactive health literacy was most strongly associated with perceived ability to exert control over healthcare compared to the other two types of health literacy. Functional health literacy was the only type of health literacy that was associated with the use of healthcare; patients with lower health literacy visited their GP more often than patients with higher health literacy. The results imply that the three types of health literacy may be relevant for various aspects of self-management. Based on both studies it could be concluded that when chronically ill are expected to be more autonomous and responsible in respect to caring for their condition, those with lower health literacy skills may need additional support in some respects.

Health literacy in the context of prevention

The aim of the third part of this thesis was to obtain insight into the extent to which health literacy is associated with psychological determinants of participation in prevention programs. Specifically, it was studied to what extent health literacy relates to psychological factors underlying informed decision-making with respect to colorectal cancer (CRC) screening and decision-making with respect to childhood vaccination. First a systematic review was presented on the relation between health literacy and informed decision-making concerning CRC screening (Chapter 6). Studies were considered relevant for inclusion if (an aspect of) informed decision-making was studied in relation to (an aspect of) health literacy in the context of CRC screening. Eight studies in which various aspects of informed decision-making regarding CRC screening were related to health literacy were considered relevant for inclusion. Seven of these studies focused on knowledge concerning CRC (screening), four on attitudes or beliefs concerning CRC (screening) and one on the perception of risk information. All studies showed either no association between health literacy and aspects of informed decision-making, or a positive association. In some studies, higher health literacy was associated with higher scores on a knowledge test and a more positive attitude towards screening. The results imply that the body of literature on the association between health literacy and informed decision-making concerning CRC screening is limited and that the heterogeneity in operationalization of both health literacy and concepts underpinning
informed decision-making make it difficult to draw conclusions.

From screening, a shift was made to childhood vaccination (Chapter 7). It was explored whether parents with higher health literacy differed from parents with lower health literacy in their preferences for characteristics of rotavirus vaccination. Chew’s Set of Brief Screening Questions (SBSQ) was used to assess health literacy. Parents’ preferences were obtained by a discrete choice experiment. The discrete choice experiment assessed parents’ preferences for out-of-pocket payment, vaccination location, the likelihood of severe side effects, protection duration and vaccine effectiveness. The results of the study showed that respondents with lower health literacy skills perceived that the vaccine’s effectiveness and the likelihood of severe side effects was less important and protection duration was more important than respondents with higher health literacy skills.

It was also found that parents with higher health literacy were less willing to participate in rotavirus vaccination when the vaccine would be offered outside the National Immunization Program; this was not the case for parents with lower health literacy skills. What this study implies is that, given the same information, parents with lower health literacy skills consider other characteristics of rotavirus vaccination as important than parents with higher health literacy. Whether this is due to differences in the understanding of information or to differences in preferences remains unclear. Nevertheless, this study calls for attention to health literacy as an important factor to consider when studying vaccination behaviour and when developing education materials.

Based on both studies it was concluded that a stronger theoretical embedment of the relation between health literacy and informed decision-making would be valuable, since the extent to which both concepts overlap and differ from each other it remains vague. Additionally, more empirical research on the relation between health literacy and informed decision-making would be valuable, to examine the extent to which both concepts relate to each other.

**Discussion and conclusion**

The studies that were described in this thesis imply that various aspects of health literacy can be distinguished and that individuals may perceive more difficulties with certain health literacy aspects than with others. The context in which health literacy skills need to be applied is influential as well; someone can have higher health literacy skills in the context of healthcare than in the context of prevention. When researchers study various aspects of health literacy and measure these aspects in distinct ways (for instance perceived difficulties versus
test scores), this leads to variation in study outcomes. Namely, in the HLS-EU project it was estimated that approximately a third of the Dutch population has health literacy skills that are problematic to inadequate. Based on the outcomes of the ALL, approximately half of the Dutch population can be expected to have poor to very poor health literacy skills. The studies that were combined in the present thesis show that health literacy, regardless of operationalization, provides a unique contribution to explaining differences in disease self-management, use of healthcare, interaction with healthcare providers, preferences with respect to vaccination, and perceived health. This in addition to determinants such as level of education, age and sex.

For researchers and healthcare providers, health literacy can be considered as an asset because it contributes to explaining variation in health-related behaviour and health. As opposed to factors such as sex, education and ethnicity, health literacy skills may be learned to some extent. This provides new opportunities for interventions that aim to strengthen Dutch citizens’ autonomy with respect to their health and care or for interventions that aim to reduce disparities in health. The concept of health literacy offers a very specific goal that can be anticipated by healthcare institutions or providers. Namely, health literacy is constituted by the interaction of individual skills and demands of the healthcare system. Therefore, it is important that healthcare organizations and healthcare providers offer information that is accessible, understandable and usable for all. The research as described in this thesis showed that health literacy is also an asset for individuals in order to exert control over their health and care.