Chapter 8

General discussion
Introduction

In the Netherlands, citizens are expected to fulfil a more autonomous and responsible role with respect to their health and healthcare. This has been motivated by various societal developments, such as more attention for the position of patients, the increase in people who suffer from a chronic condition (resulting in a call for self-management), and reforms directed at transforming the Dutch healthcare system from supply to demands regulated. The focus on individual responsibility for health and care has raised some concerns. Not every individual may be sufficiently equipped to fulfil an autonomous and responsible role, which implies for instance that individuals are expected to make well-considered decisions and to manage their disease or organize their care. In this respect, health literacy skills are considered an important factor that can contribute to individuals’ abilities to fulfil an autonomous and responsible role regarding their health and care. However, health literacy is a relatively new concept in Europe and most studies on the determinants, allied psychosocial processes and health-related consequences have been done in the USA. The overall aim of the present thesis was to provide insight into the health literacy skills of the Dutch adult population in relation to socio-economic and demographic characteristics, psychological factors, health actions and health. The research questions described in this thesis were placed in Von Wagner’s conceptual framework, in which three principal types of health actions are outlined, namely access and utilization of healthcare, patient-provider interactions and management of health and illness. The three research questions that were addressed in this thesis were as follows:

1. To what extent is health literacy associated with socio-economic and demographic characteristics and with health status?
2. To what extent is health literacy associated with (psychological determinants of) use of primary care, patient-provider interaction and self-management in the context of chronic care?
3. To what extent is health literacy associated with psychological determinants of participation in prevention programs?

In this general discussion, first the main findings of each part of this thesis are described and discussed, followed by a reflection on methodological issues. Thereafter, implications of the findings for theory development, future research, policy and practice are discussed. This chapter is round off by a general conclusion.
Main findings

Part I – Health literacy in the Dutch adult population

Research from outside of Europe indicates that health literacy is related to health outcomes and socio-economic and demographic determinants of health.⁴ In the first part of this thesis, we aimed to explore to what extent this applies to the Dutch population. Chapter 2 provided insight into the health literacy skills of the Dutch general population in relation to socio-economic and demographic characteristics based on data obtained from the 2012 European Health Literacy Survey (HLS-EU).⁵ The HLS-EU provided the first Dutch health literacy measure from a broad perspective on health literacy (conceptualizing health literacy as a multidimensional concept). The instrument that was developed and used for the purpose of the HLS-EU draws a distinction between four health literacy skills: accessing, understanding, appraising and applying. The instrument measures to what extent individuals perceive difficulties with these skills with respect to the domains of healthcare, disease prevention and health promotion. Across all domains, on a scale from 1 (lowest score) to 4, mean scores ranged from 3.1 for perceived difficulties with appraising information to 3.4 for perceived difficulties with understanding information.

However, the difficulties respondents perceived with the four health literacy skills, varied to some extent per health domain. For instance, accessing information was perceived as more difficult in the domain of healthcare (mean 2.6) than in the domain of disease prevention (mean 3.4). In general, individuals with a lower level of education and a lower self-reported social status perceived more difficulties regarding all four skills than those who had a higher level of education and reported a higher social status. In addition, males perceived more difficulties than females regarding all four skills. Age was negatively associated with accessing and understanding health-related information, but was not associated with either appraising or applying health-related information. Thus elderly do not seem to differ from younger adults regarding their ability to judge and use health-related information, but they do differ from younger adults regarding their ability to access and understand health-related information. These associations varied according to the domain that was addressed. The results imply that when health literacy is measured as a set of skills to be used in various contexts, associations with socio-economic and demographic characteristics can vary according to these skills and contexts.

Literature suggests that health literacy may be an explaining mechanism in the association between educational attainment and health, since health literacy
is found to be associated with both level of education as well as health outcomes. However, few studies have actually examined this. Therefore, in Chapter 3, it was explored to what extent health literacy constitutes a pathway in the association between education on one hand and perceived general, physical and mental health on the other. For this purpose, data from the 2008 Adult Literacy and Life Skills Survey (ALL) were used including the Health Activities and Literacy Scale (HALS). The HALS is based on a selection of health-related reading and problem-solving tasks developed according to measurement methods that stem from the educational field, to measure individuals’ performances. A relatively high percentage of the respondents demonstrated poor (43.4%) or very poor health literacy (10.6%), which was associated with their level of education; those who were more highly educated had higher health literacy scores. Furthermore, it was found that those with higher health literacy reported better self-reported general, physical and mental health. 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 means that having lower health literacy skills partly explains the association that was found between having a lower level of education and reporting poorer health.

Regardless of the differences in the conceptualization of health literacy, in line with literature, both studies indicate that health literacy is associated with indicators of socio-economic status and demographic characteristics and in part accounts for the association between educational attainment and perceived health.

**Part II – Health literacy in the context of chronic care**

Adults who suffer from a chronic condition are likely to be more frequently involved with healthcare and self-care activities than adults who do not suffer from a chronic condition. This means that relatively often, a demand is made on the health literacy skills of this population. 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) use of primary care, patient-provider interaction and self-management among adults with a chronic condition. In this respect, we focused in Chapter 4 on diabetes self-management and in Chapter 5 on control over care among Dutch adults with various chronic conditions. Self-management and control over care are explicitly stimulated by Dutch healthcare standards for chronically ill patients.
In the conceptual model of Von Wagner and colleagues, it is described that health literacy relates to the management of disease via psychological determinants like knowledge. Therefore, in Chapter 4, a study was described that examined whether diabetes knowledge constitutes a pathway between health literacy and diabetes self-management. Self-management encompasses various behaviours related to the monitoring and care for one’s condition. These behaviours can be used as indicators of self-management. In the study as described in Chapter 4 smoking behaviour, physical activity, self-control of glucose levels, monitoring of glucose levels and HbA1c level, were included as diabetes self-management indicators. HbA1c level is not a behaviour but was perceived as an indication of the extent to which a person manages his or her diabetes. Higher HbA1c levels may indicate poorer self-management.

Analyses were performed on a cross-sectional sample of patients with predominantly type 2 diabetes obtained from patient registrations and questionnaires completed in 2010. Health literacy was assessed by the Set of Brief Screening Questions (SBSQ). The mean score on this short indicator of health literacy, was found to be related to knowledge of diabetes and certain indicators of self-management behaviour. No significant association was found between health literacy and self-reported monitoring of glucose levels and between health literacy and smoking. However, 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.

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 were less likely to smoke, compared to those with less knowledge. No associations were found between diabetes knowledge and the other self-management indicators. Finally, diabetes knowledge mediated the association between health literacy and glucose self-control and between health literacy and smoking. This indicates that those who have lower health literacy skills are less likely to control their glucose levels themselves, partly because they have less knowledge of diabetes. With respect to smoking this implies that respondents with lower health literacy are more likely to smoke when they have less diabetes knowledge.

The results of the study described in Chapter 4 indicate that the association between health literacy and self-management of diabetes is not straightforward and depends on the type of self-management behaviour. For instance, no association between health literacy and monitoring of glucose levels was found, but health literacy was associated with physical activity. This nuances the
theoretical model of Von Wagner and colleagues.3 Namely, the findings imply that the presence of an association between health literacy and disease self-management, depends on the type of actions that are preformed to manage a disease. The results also imply that knowledge is more important for certain self-management tasks than for others. Efforts to increase diabetes knowledge may therefore not always lead to better outcomes among those with lower health literacy. Thus, both diabetes knowledge as well as health literacy skills seem important targets for interventions to promote diabetes self-management, since targeting both is likely to lead to improvements on more self-management aspects than targeting only health literacy or knowledge.

Where Chapter 4 focussed on health literacy and disease specific self-management activities, Chapter 5 reflected on health literacy in relation to perceived control over care. Chapter 5 also described the relation between health literacy and frequency of general practitioner (GP) visits. The study in which this was explored, was based on a sample of disabled adults and chronically ill (including individuals with diabetes, cardiovascular disease, lung disease and musculoskeletal disease). Thereby, a distinction was made between functional, interactive and critical health literacy as assessed by the Functional, Communicative, Critical Health Literacy scale (FCCHL).22 Functional health literacy reflects basic skills in reading and writing to be able to function effectively in everyday situations. Communicative/interactive health literacy reflects more advanced cognitive, literacy and social skills, that can be used to actively participate in everyday activities, extract information and derive meaning from different forms of communication and to apply new information to changing circumstances. Critical health literacy refers to more advanced cognitive skills, which together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations.23

Perceived control over care (i.e., the ability to steer the care process to some extent) was indicated by perceived ability to organize care, interact with healthcare providers and perform self-care. The study showed that after controlling for various patient characteristics, higher interactive health literacy appeared to be the type of health literacy that was most strongly associated with less perceived ability to exert control over care compared to the other two types of health literacy. Critical health literacy was not associated with patients' perceived ability to exert control over care when adjusting for functional and interactive health literacy. Furthermore, functional health literacy was the only type of health literacy that was associated with the use of primary care; patients
with lower functional health literacy visited their GP more often than patients with higher functional health literacy (after controlling for perceived health status). This suggests that patients with lower functional health literacy may need more support from their GP in caring for their condition than patients with higher functional health literacy. Patients with lower health literacy skills may be less able to discern between more serious symptoms that require the attention of their GP and lighter health problems which they should be able to handle themselves.

This study reflected on various components of the conceptual model of Von Wagner. Namely, on the ability to organize care (an aspect of the volitional phase), on the management of disease, on interaction with healthcare providers and on use of care (three types of health actions). The associations as proposed by Von Wagner, between health literacy and health actions as well as organizing care, were confirmed in this study. However, the associations varied per type of health literacy; functional, interactive and critical health literacy seem to be relevant for distinct health actions/aspects of exerting control over care.

To summarize, the findings presented in this part of the thesis indicate that adults with a chronic condition that have higher health literacy skills seem better capable of organizing care, interacting with their healthcare provider and managing their disease. However, the study described in Chapter 5 shows that specific aspects of health literacy relate distinctly to perceived control over care. The skills needed to find, understand and apply relevant information and express ones thoughts are especially important in this respect (interactive health literacy). This means that initiatives to strengthen individuals’ position in the care of their condition may be more effective when they are directed at interactive health literacy skills.

In the studies that were described in this part of the thesis, knowledge concerning a chronic condition was included as a determinant of health actions (Chapter 4) as well as a determinant of health literacy (Chapter 5). The relation between health literacy and knowledge is complex since there is yet not an univocal theory on how both concepts relate to each other. Knowledge is considered by some scholars to be part of health literacy, whereas others consider it to be a unique construct. According to Von Wagner’s conceptual model, previous knowledge about a specific health-related topic, like a chronic condition, can strengthen health literacy skills. In this respect, knowledge is a determinant of health literacy, which is the way it was conceptualized in the study described in Chapter 5. On the other hand, Von Wagner’s model suggests that health literacy skills can also increase knowledge; someone with higher
health literacy skills may be more likely to incorporate information on certain health-related issues than someone with lower health literacy skills. In the study described in Chapter 4, knowledge was related to health literacy in line with this view. Although health literacy and knowledge are related constructs, the studies described in Chapter 4 and Chapter 5 indicate that health literacy and knowledge provide unique contributions in explaining variance in self-management, perceived control over care and frequency of GP visits.

Part III – 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, the extent to which health literacy relates to decision-making with respect to colorectal cancer (CRC) screening and childhood vaccination was studied. According to Von Wagner’s conceptual model, lower health literacy is related to lower participation in prevention programs via psychological processes. This includes factors that are related to decision-making regarding preventive behaviour (e.g., attitude, knowledge, perceived barriers and benefits and decision-making skills). In the two chapters included in the third part of this thesis, it was described how health literacy relates to these psychological processes.

In Chapter 6, a systematic review was presented on the relation between health literacy and informed decision-making concerning CRC screening. Informed decision-making can be interpreted as a process, including various stages of decision making (from the awareness of the decision problem (like the possibility to participate in screening) to the actual decision that is made). Informed decision-making can also be interpreted as an outcome of sufficient knowledge combined with a decision that is consistent with a person’s attitude toward a decision problem. For the purpose of this review, a broad approach to the concept informed decision-making was adopted, including factors related to various stages of the decision-making process (awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation) as well as an informed decision as the outcome of this process (sufficient knowledge in combination with deliberation and attitude-uptake consistency). Studies were considered relevant for inclusion when (an aspect of) informed decision-making (awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation) was studied in relation to (an aspect of) health literacy (accessing, understanding, appraising, applying) in the context of CRC screening. Eight studies 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 in relation to health literacy. All studies showed either no association between health literacy and aspects of informed decision-making, or a positive association. Namely, in some studies higher health literacy was associated with higher scores on a knowledge test and a more positive attitude towards screening. But the body of literature on the association between health literacy and informed decision-making concerning CRC screening is limited. Therefore, more research is needed to determine whether there is indeed a positive association between health literacy and informed decision-making concerning CRC screening. Additionally, an important topic for further research would be what knowledge would be essential for people with higher and lower health literacy skills to make informed decisions for participation in screening programs.

Vaccination is, next to screening, an important action to prevent disease. In the Netherlands, individuals generally receive various vaccinations during childhood, offered in the National Immunization Program (NIP). In Chapter 7, it was explored whether parents with higher health literacy differed from parents with lower health literacy concerning their preferences for the characteristics of rotavirus vaccination. The rotavirus vaccine may become part of the Dutch NIP. Following Von Wagner's conceptual model, preferences could be interpreted as a form of attitude. A person can have positive or negative feelings towards characteristics of rotavirus vaccination. These preferences could influence individuals' decisions to participate in prevention services such as vaccination.3

Chew's Set of Brief Screening Questions (SBSQ) was used to assess health literacy.19-21 Parents' preferences were obtained by a discrete choice experiment (DCE). The DCE assessed parents' preferences regarding out-of-pocket payment, vaccination location, likelihood of severe side effects, protection duration and vaccine effectiveness. The results of the study show that respondents with lower health literacy skills perceived vaccine effectiveness and the likelihood of severe side effects to be less important and protection duration to be 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 was offered outside the NIP, while this was not the case for parents with lower health literacy skills.

What this study implies is that given the same information (i.e., information presented in the same format and with the same content), the characteristics of rotavirus vaccination that parents with lower health literacy skills considered as important differed from those considered important by parents with higher
health literacy. Whether this is due to differences in the understanding of information or to distinct preferences remains unclear. Nevertheless, this study calls for attention on health literacy as a factor to consider when studying vaccination behaviour and developing education materials. Regardless the cause for differences in preferences, parents with lower health literacy may decide differently when rotavirus vaccination is offered based on certain characteristics than parents with higher health literacy.

**Methodological considerations**

**Health literacy measurements**
Reliable, valid, and feasible measurement of the concepts under study is one of the most challenging aspects of research. In the present thesis, various instruments to measure health literacy were applied including the European Health Literacy Survey Questionnaire (HLS-EU-Q); the Health Activities and Literacy Scale (HALS); the Set of Brief Screening Questions (the SBSQ); and the Functional Communicative and Critical Health Literacy questionnaire (the FCCHL). All of these instruments can be considered reliable based on their psychometric properties, but the instruments differ in how they measure health literacy and in what aspects of health literacy are measured. In this paragraph, these two characteristics of the health literacy instruments that were used in the current thesis will be elaborated. In addition, considerations concerning the interpretation of health literacy scores will be described.

**Subjective versus objective health literacy**
The first distinction between health literacy instruments can be made based on how health literacy is measured: subjectively or objectively. The HALS is an objective assessment of health literacy, based on scores on a range of tasks that measure health-related prose and document literacy, numeracy and problem-solving skills. On the other hand, the HLS-EU-Q, the SBSQ and the FCCHL measure self-reported difficulties with health-related information. Both methods of measuring health literacy have their strengths and limitations. Subjective measures of health literacy may reflect an overestimation of peoples’ health literacy skills, since generally people tend to overestimate their skills.28-30 However, a limitation of objective health literacy measures is that it remains unclear to what extent individuals’ assessed performances on health-literacy tasks can be considered a problem in their daily life. Namely, when systems and
information are poorly accessible, those with high health literacy scores may still perceive difficulties in their daily life. For example, someone who easily fulfils reading tasks, may perceive difficulties with finding the right information on treatment options. On the other hand, those with lower health literacy might find ways to circumvent difficult demands of the system, e.g. by mobilizing social support from relatives or friends. Another limitation is that objective health literacy measures should be administered in person and therefore they are more difficult to include in questionnaire-based survey research.

Objective health literacy measures, such as the HALS, are especially useful to determine differences in performances between individuals, groups or countries or to measure changes in health literacy skills over time on a population level. In addition, subjective health literacy measures, such as the HLS-EU-Q, provide insight into perceived problems in daily life and health domains that may need special attention. Measures like the HLS-EU-Q include items that are more considerate of the context in which health literacy skills need to be applied and thereby provide more insight into actions that could be taken to improve health literacy, opposed to objective health literacy measures. It can be concluded that objective and subjective health literacy measures provide insight into health literacy in different ways and therefore complement each other.

Aspects of health literacy
The instruments as used in the present thesis not only measure health literacy in multiple ways, but also measure distinct aspects of health literacy. The HLS-EU-Q covers three domains of health (healthcare, disease prevention and health promotion) and addresses four types of skills (assessing, understanding, appraising and applying). The FCCHL is less extensive than the HLS-EU, but also provides insight into specific aspects of health literacy by measuring functional, interactive and critical health literacy skills. On the other hand, the SBSQ provides a relatively limited measure of health literacy, since it makes no distinction between skills or health literacy types and is merely directed at the context of healthcare. The HALS includes a broad range of tasks over various health domains, but is directed only at written health-related information. Although various aspects of health literacy are measured (and some health literacy instruments are broader than others), most studies on health literacy show results in a similar direction, including the ones as described in this thesis. That is, lower health literacy tends to be associated with poorer health-related outcomes, such as poorer perceived health. This could imply that the various health literacy instruments measure aspects of a similar latent construct.
Although a multidimensional concept can be difficult to study, because it complicates the comparability of findings, it is important that health literacy instruments aim to draw a distinction between multiple aspects. This will provide insight into which specific aspects of health literacy affect certain outcomes. Instruments that measure multiple aspects of health literacy (like the FCCHL and the HLS-EU-Q) can provide insight into the relative scores of people on these aspects (for instance some people may score low on functional health literacy, but higher on interactive health literacy). This can help determine the specific health literacy aspect that should be addressed when aiming to improve the use of health information. Furthermore, insight into various aspects of health literacy may help researchers and healthcare providers to think in terms of health literacy profiles instead of high versus low health literacy. This is useful for healthcare organizations to get a grasp on how they can best serve particular groups.

**Interpretation of health literacy scores**

Since many conceptualizations of health literacy and various health literacy instruments are available, health literacy scores can be complex to interpret. For instance, both the HLS-EU-Q and the HALS provide insight into the health literacy skills of the Dutch adult population. However, because there is no golden standard for the measurement of health literacy, it is difficult to determine what percentage of the Dutch adult population actually has lower health literacy skills. The HLS-EU-Q was assessed in eight European countries and based on the cut-off points that were chosen in the context of the HLS-EU project, the Netherlands performed relatively favourable compared to the other countries. Nonetheless, the HLS-EU implied that 26.9% of the Dutch population aged 16 years or older has problematic and 1.8% inadequate health literacy skills. This total percentage of 28.7 differs remarkably from the more than 50% that are expected to have poor to very poor health literacy based on the HALS results. This implies that the conceptualization and measurement of health literacy determines the indication of the amount of people who have lower health literacy skills.

The cut-off points for lower and higher health literacy skills are more established for the HALS scores than for the HLS-EU-Q, the SBSQ and the FCCHL scores. However, whether a person has sufficient health literacy skills, regardless the type of instrument that has been used, depends highly on the context, the social environment and demands of the healthcare system. For instance, when people find themselves in a stressful or otherwise uncomfortable
situation and experience fear, distress or pain, it may be more difficult to understand, appraise or use information than in a comfortable situation. Furthermore, as indicated by the study described in Chapter 2, some health domains may be more complex than others and the extent to which people have sufficient health literacy skills may differ according to domain or content. In addition, in daily life, individuals may receive help from their family and friends when managing the understanding and application of health-related information. This could temper the adverse effects of lower health literacy in practice. Furthermore, the demands of the healthcare system may determine the meaning of health literacy scores. When health information is poorly accessible or difficult to understand, health literacy scores have different implications in daily life than when information is highly accessible and easily understood. Namely, in both scenarios, certain levels of health literacy could be sufficient to function in daily life. Additionally, it has been suggested that someone’s health literacy skills may vary throughout the life course. For instance, health literacy skills may increase through certain (disease-related) experiences, or health literacy skills may decrease due to age-related cognitive decline. Taking all these issues into consideration, one should be cautious about categorising people as having high or low health literacy. A person can have higher health literacy skills in a particular situation or point in time and lower health literacy skills in another situation or another point in time.

**Limitations**

The studies described in this thesis have limitations. The study samples used in the separate chapters are likely to be subject to selection bias. First, ethnic minorities were underrepresented in the samples in which information on ethnicity was available, ranging from 8% (in Chapter 7), 9% (in Chapter 5) to 13% (in Chapter 3 and Chapter 4). The percentage of ethnic minorities in the Dutch adult population aged 20-65 was approximately 22.5% in 2013 (10.2% of Western origin and 12.3% non-Western). Studies from North America imply that members of minority populations show lower health literacy skills than adults from the majority population (for example). However, if ethnic minorities participate in health literacy research, their scores on health literacy instruments may be influenced by difficulties filling in questionnaires or misinterpreting the questions due to difficulties with the native language. Therefore, lower scores may reflect language difficulties. It is questionable whether this can be considered a reflection of lower health literacy.

In addition to ethnic minorities, Dutch adults with low literacy skills are also
likely to be underrepresented in the studies that were included in the present thesis. It was estimated that in 2008, 10% of the Dutch population between 16 and 65 years of age had low literacy skills.\textsuperscript{34} This does not include those who are close to illiteracy (2.5%), but it may include individuals with disorders like dyslexia or dyscalculia. Basic arithmetic and reading skills are considered to be the foundation of health literacy as suggested by Von Wagner and colleagues.\textsuperscript{3} Since those who have poor basic arithmetic and reading skills seem likely to be underrepresented in the studies described in the present thesis, the estimations of the number of people who are likely to have lower health literacy skills may be higher in real life.

Another limitation of the present thesis is that the included studies focused on socio-economic and demographic characteristics and various (psychological determinants of) health actions in relation to health literacy, in line with the conceptual model of Von Wagner. What was not included in this model and also not described in the present thesis, is how health literacy relates more intuitive or routine driven behaviour. Namely, health-related behaviour can be based on routines rather than for instance attitude, knowledge or the weighing of pros and cons \textsuperscript{26,35} Furthermore, emotions like fear and distress could affect the use of health literacy skills. How health literacy relates to these types of emotions was not part of the present thesis, but would be relevant to address in future research. Furthermore, the theoretical embedment of health literacy in relation to psychological factors as well as health actions remains limited. Although the theoretical model of Von Wagner and colleagues is very valuable for the guidance of research, the theoretical distinction or overlap between the included concepts remains unclear.\textsuperscript{3}

Another limitation of the studies as described in the present thesis, is that the studies were based on cross-sectional data. Therefore no inferences could be made on the direction of the associations that were found.

**Discussion of main findings**

The studies described in this thesis underline that health literacy could be regarded a multidimensional concept of which various aspects can be measured. This includes the ability to read and understand different types of health-related texts in print, but also the ability to understand verbal and digital health-related information, the ability find this information and to judge and use it. Based on the studies as described in this thesis, these can be considered key-aspects of
health literacy.

The findings also imply that aspects of health literacy can differ in their complexity. For instance, the study described in Chapter 2 implies that Dutch adults perceive more difficulties with appraising health-related information compared to accessing, understanding and using information. Health literacy skills also depend on the context in which they need to be applied: information in the context of healthcare seems more easy to access, understand, judge and use than information in the context of prevention. In addition, the findings indicate that specific aspects of health literacy can be relevant for specific health actions. Interactive health literacy seems for instance more relevant for people’s ability to organize care than critical health literacy.

In the present thesis, the scores on the health literacy instruments were mainly interpreted as an indication of personal skills. However, the subjective health literacy measures that were applied may not only provide an indication of personal skills, but can also be interpreted as the complexity of a healthcare system. For instance, if respondents state to perceive difficulties with understanding what their doctor says to them, this could imply that the information is unclear or too complex. Furthermore, health literacy scores can be interpreted as an indication of the balance between individuals’ skills and demands of a healthcare system or demands of society at large. For instance, when comparing health literacy scores between countries, as was done in the European Health Literacy Survey, health literacy scores can be informative about individuals’ skills in light of the functioning or demands of healthcare systems or societies, or the other way around. Health literacy as the balance between individuals’ skills and demands of a system/society should receive more attention in future research. This approach implies that solutions for lower health literacy should come from two sides: the side of individuals as well as the side of systems (information providers).

Based on the findings of the studies as described in this thesis, health literacy can be considered an asset for public health in multiple ways. In the first place, it can be considered an asset in the way Nutbeam proposed: health literacy skills help people to exert control over their health and care.23 Namely, those with higher health literacy skills were found to be better able of performing certain self-management tasks in the care for their chronic condition, interact with health-care providers, and to organize care. Health literacy can be considered an asset for public health researchers and healthcare providers. Namely, health literacy was found to provide a unique contribution to explaining variation in health actions and in perceived health. Furthermore, health literacy is a factor
that may be modifiable through interventions, unlike factors such as age and sex. Health literacy therefore offers new opportunities for the development of interventions to reduce disparities in health or to strengthen the autonomy of individuals regarding their health and care.

**Implications**

Based on the findings of the present thesis and in light of the current knowledge base concerning health literacy, implications were formulated with respect to theory development, research, practice and policy.

**Implications for theory development**

*Conceptualization of health literacy*

The studies that were described in this thesis illustrate that health literacy can be conceptualized in various ways. The debate on the definition and measurement of health literacy continues. Given the variety in definitions of health literacy from several points of view and the discussion on whether to speak of one or multiple health literacies, it is questionable whether one definition is feasible or useful. Perhaps a general conceptualization would be more suitable to enhance the research field on health literacy instead of striving for a single definition. A general concept represents a characterization of a generally agreed-upon direction in which to look, whereas a definition implies set boundaries and a precise meaning. Instead of adopting a precise definition of health, she proposed formulating health as the ability to adapt and self-manage. This formulation was not labelled as a definition, but as a general conceptualization. In an era in which knowledge is generated at a high speed, talking about a general concept of health literacy seems suitable since it leaves room for multiple interpretations or operationalizations. Nevertheless, studies that measure health literacy should clearly state what aspect of health literacy is being measured, but all can contribute to insight into the general concept health literacy.

*Theoretical embedment of health literacy*

According to the model of Von Wagner, health literacy is related to various psychological processes, as well as to basic skills in reading and writing. But how health literacy exactly differs from these concepts remains largely unclear. It is
recommended that more efforts are undertaken to strengthen health literacy theoretically, thereby clearly describing how health literacy relates to concepts such as knowledge, attitude/beliefs, motivation and informed decision-making.

Implications for research

Health literacy as sample characteristic

In line with literature, the studies that are combined in the present thesis imply that health literacy is related to individual characteristics such as level of education, age and sex, but that it provides a unique contribution in explaining differences in behaviour and health-outcomes. Therefore, it is recommended to include health literacy measures in research that aims to explain differences in health or health-related behaviour, such as self-management or screening participation, and to report it as a sample characteristic in addition to education, ethnicity, sex and age. Currently, this is not common as illustrated by the review on health literacy and CRC screening described in Chapter 6.

Developing and retaining health literacy skills

Health literacy seems to a certain extent learnable and by some considered an outcome of health education. Von Wagner and colleagues suggest that basic skills in reading and arithmetic as well as cognitive abilities are important determinants of health literacy skills. However, health literacy can also be modified by experiences throughout people’s life course (experiential learning). This implies that individuals’ health literacy skills could be modified through interventions. The review of Berkman and colleagues (including English literature) reveals that a number of interventions have a positive impact on health literacy skills. However, there are hardly European studies that examined the effects of interventions on health literacy.

Furthermore, research on how to retain health literacy skills is currently lacking. Some state that health literacy can be considered as a ‘use it or lose it’ phenomenon, implying that skills should be practiced in order to be retained. In this context it has been suggested that frequent reading may have a positive effect on health literacy skills, i.e., on functional health literacy skills. Based on the data we had at our disposal, higher health literacy was found to be associated with a higher frequency of reading (not reported). However, the drawback of cross-sectional data is that it is not possible to determine the direction of associations. It is possible that reading behaviour does not influence health literacy, but reading frequently is a characteristic of those who have higher health literacy skills. Longitudinal research is needed to study how health...
literacy can be retained and whether reading behaviour is a relevant determinant in this regard. Another expected determinant of retaining health literacy skills is age-related cognitive decline. Von Wagner and colleagues suggest in their model that age-related cognitive decline can negatively affect the procession of information.\textsuperscript{39} It would be relevant to examine what aspects of health literacy may be affected by cognitive decline. Since the Dutch population is aging, which will lead to an increase in the number of people who suffer from a chronic condition, this is a relevant topic for future research.

\textit{Health literacy and decision-making}

In the current thesis, attention was paid to the relation between health literacy and elements of decision-making, although not in great depth. It would be relevant to obtain a better understanding of the relation between health literacy and decision-making, especially informed decision-making. Informed decision-making is increasingly regarded the goal of information on prevention such as cancer screening. The study described in Chapter 7 implies that adults with lower health literacy skills have different preferences when deciding on rotavirus vaccination for their newborn than parents with higher health literacy. Whether this reflects real differences in preferences or rather differences in how information is understood should be studied in more depth. Future studies may also address whether people with lower and higher health literacy differ in their decision-making strategies and in their information needs. For instance, topics could include whether certain types of information like numerical information or more abstract information are perceived or used distinctly by individuals with higher and lower health literacy skills. Another topic might be to what extent individuals with higher and lower health literacy differ in basing decisions on the deliberation of the pros and cons of a decision option, on emotions or on social influences. Furthermore, more insight is needed in what information is required by individuals when they have to make health-related decision, such as participation in cancer screening, and whether these information needs differ according to someone’s health literacy skills. Insights in this regard could help when developing education materials.

\textit{Enhancing the research field of health literacy}

Health literacy is a relatively new research topic, that has received little attention, especially in Europe. But in the past decennia, the research field of health literacy has expanded. There has been many discussion on how to define and measure health literacy. Most studies on health literacy so far, are based on
cross-sectional data. In order to advance the research field, there is a need for research on the effectiveness of interventions to enhance health literacy. Research on interventions could support healthcare providers in determining how they could serve patients with lower health literacy skills. It could also enhance theory development regarding health literacy (for instance how health literacy skills can be obtained or enhanced). Furthermore, longitudinal research designs are needed, in order to study the development of health literacy skills throughout the life course.

**Implications for practice**

*Maintaining or increasing health literacy skills*

Efforts to strengthen or to maintain individuals’ health literacy skills are relevant for public health, since this thesis indicates that having higher health literacy is related to better health-related outcomes. Based on theory concerning skill development in general, investments early in life, even before formal education, are considered to be an important contributor to skill formation. Furthermore, skills can be obtained during a person’s life course by experiences and formal or informal learning opportunities, which are also incorporated in the conceptual framework of Von Wagner and colleagues. This implies that efforts to maintain or to increase health literacy skills may be needed at several points in time during one’s life course. For instance, basic skills in reading and arithmetic, the foundation of health literacy, can be addressed during formal education and by informal educational opportunities early in life. Health literacy as measured by the HALS may relate to these types of entrances to skill development. The skills to interact with the healthcare system, obtain relevant information and use information for the benefit of one’s health may be addressed later in life. These are the type of skills that go beyond the ability to correctly interpret and use information in print.

In this regard, it may be helpful to draw a comparison with the concept of intelligence. In psychology, a distinction is often made between fluid intelligence and crystallized intelligence. The first form of intelligence refers to one’s working memory and the capacity to obtain new information. This type of intelligence is thought to increase until approximately the age of 20, and thereafter decreases gradually with age. Crystallized intelligence refers to long-term memory and is thought to reflect problem-solving skills that are gained through knowledge and experience. Researchers may want to draw a similar distinction between health literacy skills: skills that are fluid (e.g., the capacity to understand and learn) and skills that are crystallized (e.g., the capacity to
correctly monitor blood glucose levels). When aiming to increase functional health literacy skills among the general population, fluid skills may need to be addressed early in life, for instance by addressing them in school curriculum. In order to increase interactive and critical health literacy skills, more crystallized skills may be needed, for example, by teaching patients how to monitor their glucose levels.

**Efforts from healthcare organizations and providers**

In addition to focusing on individuals’ skills, it is important to address the healthcare system as well. Health literacy can be considered as a balance between individuals’ skills and healthcare system demands. From this perspective, efforts to increase or maintain individuals’ skills should be counterbalanced by efforts to make health-related information accessible and understandable. Demands of a healthcare institution can increase or decrease the barrier for individuals with lower health literacy to access relevant health information, as is suggested by the model of Von Wagner. Organizations that make it easier for people to navigate, understand, and use information and services to take care of their health are referred to as ‘health literate organizations’ in the literature.

Given the increasing amount of health information that is available today, healthcare professionals should assume the task of informing their patients about information sources, including webpages that contain useful information on health and healthcare. The study described in Chapter 2 implies that Dutch adults relatively frequently perceive difficulty appraising health-related information compared to accessing, understanding and using information. Appraising information can be interpreted in two ways: judging whether information is reliable or judging whether information is relevant for one’s personal goals. Appraisal in the first interpretation can be very complex given the amount of health-related information that is available to date and whose reliability is often hard to determine. Therefore, healthcare professionals may need to take an advising role and inform patients about trustworthy (online) information.

The second interpretation of appraising information is addressed by decision aids. Decision aids can help people make decisions that are in line with their preferences. It is important that the usability of future decision aids for individuals with lower health literacy is taken into consideration. In order to judge whether information is personally relevant, information should be understandable. With respect to health information accessibility, it may be
fruitful to invest in applications that enable people to choose the level of complexity of a given (web) text.

**Implications for policy**

Currently, Dutch health policy lays great emphasis on personal responsibilities and citizen autonomy. Some scholars state that a unilateral emphasis on citizens’ autonomy could enhance polarization in society and health outcomes. Therefore, it is suggested that emphasis on personal autonomy, which has positive aspects, is counterbalanced with initiatives to support those who find it difficult to exert autonomy with respect to their health and care. More specifically, efforts need to be undertaken to ensure that information on health-related issues (like information on health insurances or information on cancer screening) is accessible and understandable for all. Currently, there are a number of laws in the context of health and care, in which clear information provision is made explicit. The Dutch Law of Agreement to Medical Treatment (WGBO) says that all clients have the right to receive understandable information regarding their disease and treatment. And the European law on the provision of food information to consumers (EU Regulation 1169/2011) was called into being to improve the information (including the legibility) that is provided on food labels.

Thus, there seems to be attention for individuals’ needs for understandable information. Nevertheless, the act on individuals’ right to understandable information could be generalized to other health-related contexts. For instance to the insurance sector where consumers have to decide what type of insurance would fit their needs. In order for people to make well-considered decisions, accessible and understandable information is essential. This also yields for national screening programs. Invitations for screening should be understandable, also for those who have lower health literacy skills. Individuals tent to neglect information that is too complex to understand, which is a barrier for informed decision-making. Therefore, it is recommended to invest in the development of guidelines regarding the type of characteristics on which accessible and understandable information should comply, for fields that relate to public health. If healthcare policy presumes that individuals make informed decisions regarding their health and care, policymakers should make assure that individuals are provided information that can be used to make informed decisions.
General conclusion

Health literacy is a multidimensional construct that can be operationalized in multiple ways. About a third to half of the Dutch adult population is expected to have relatively low health literacy skills, based on two distinct health literacy surveys. These individuals are likely to face difficulties in fulfilling the autonomous and responsible role with respect to their health and care that is nowadays expected of Dutch citizens. This thesis indicates that regardless of the operationalization, lower health literacy is related to indicators of a lower socio-economic position, older age and poorer perceived health status. Lower health literacy is also related to indicators of lower self-management abilities and a higher use of primary care. Subsequently, this thesis implies that health literacy is related to psychological factors underpinning informed decision-making with respect to screening and vaccination. Efforts that can increase or maintain people’s opportunities as well as their abilities to access, understand, appraise and apply health-related information may be beneficial for people’s health outcomes as well as for their ability to exert control over their health and care. Health literacy can be considered a balance between individual skills on the one side and system demands on the other side. Therefore, it seems most effective to offer interventions to increase or maintain health literacy from both angles. It can be concluded that health literacy is an important asset for individuals to exert control over their health and care. Health literacy is also an asset for researchers, healthcare providers and policy makers, since it provides a unique contribution to explaining differences in health actions and health outcomes.
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