Chapter 1

Introduction
In the past decennia, in the Netherlands and other Western countries, citizens have increasingly been expected to fulfill an autonomous and responsible role when it comes to their health and healthcare. This has been motivated by various societal developments:

1. A number of legal reforms were introduced in the 1990’s that were directed at strengthening a patient’s position in healthcare (e.g. the Dutch Law of Agreement to Medical Treatment (WGBO)). Simultaneously, ‘patient-centred care’ became an important perspective as increased attention was given to patient preferences in healthcare practices and the involvement of patients. For example, whereas in the past, healthcare providers predominantly made treatment decisions, shared decision-making has increasingly become the point of departure.

2. Another development is the aging population in the Netherlands, which leads to a growing number of elderly citizens with one or more chronic health conditions. This leads to an increase in healthcare needs as well as a decrease in potential labour force in the healthcare sector. Therefore, changes in the healthcare system are needed to meet the healthcare needs of individuals with a chronic condition. In this respect a strong call for patient self-management has been made. Self-management is directed at enabling patients to take care for their disease independently, for instance by stimulating healthy behaviours and monitoring the symptoms of a condition. This requires that patients fulfil an active role in the care for their disease.

3. In 2006, reforms directed at transforming the Dutch healthcare system from a supply to a demand regulation have also contributed to the increased focus on citizens’ autonomy and responsibility with respect to health and healthcare. This includes the introduction of the Health Insurance Act (Zvw) and the Act on Market Regulation in Healthcare (WMG). These reforms were intended to reorganize healthcare on a regulated-market basis and thus, Dutch citizens became more important as stakeholders in the system. As a result, individual Dutch citizens now need to make personal choices among insurance companies and healthcare providers.

More room for autonomy and individual responsibility with respect to health and healthcare can be considered a positive development, since it meets the human value that individuals should be free to decide what is best for his or her health. On the other hand, the focus on individual responsibility for health has raised some concerns. For example, some question whether every individual is...
able to make well-considered decisions and whether those who are already
disadvantaged when it comes to their health become even more disadvantaged,
since they may be less equipped to manage their disease and organize their care.

In order for patients and citizens to fulfil an active and responsible role
regarding their health and healthcare, people need various competences.
Competences encompass characteristics such as knowledge, skills, mind sets and
thought patterns. Individuals with more or better developed competences may
have a higher opportunity of obtaining or maintaining the best possible state of
health and receiving the care they need compared to those with less or less
developed competences. For instance, individuals who are more knowledgeable
about the benefits of taking medication correctly may be advanced with respect
to their health compared to those who are less knowledgeable in this regard.

The same applies to skills, including the skills to obtain and use health- and
healthcare-related information. Those who have the skills to obtain relevant
information and to understand and judge it, have a greater opportunity to find
the care they might need or to learn about their health and hazards for their
health than those who are less skilled. However, not everyone is able to obtain
the right information, understand or judge it, or use it to the benefit of their
health or the health of others. This specific set of skills is referred to by the term
‘health literacy’. The World Health Organization (WHO) stresses the importance
of increased attention for health literacy in research, policy and practice, since it
is the right of individuals to have access to health information and health systems
that they can understand and navigate. The importance of health literacy for
health and health-related behaviour among the Dutch population will be the
central theme of this thesis.

Health literacy

Health literacy skills reflect the ability to access, understand, appraise and use
health-related information in various domains. Important domains in this
regard are healthcare and prevention. In general prevention refers to the
prevention of disease (e.g., vaccination and screening), the promotion of health
(e.g., stimulation of a healthy lifestyle) and the protection of health (e.g., quality
control of drinking-water). In the current thesis, the term prevention will refer
to the prevention of disease by vaccination or screening.

Health literacy skills are relevant when it comes to understanding
information from healthcare providers, as well as information in print from
newspapers or medication leaflets and digital information from websites. In part, interest in health literacy is driven by its potential contribution to individuals’ ability to exert control and make personal decisions with respect to their health and healthcare. Individuals who have better access to information sources and who are better able to understand information are more likely to internalize the information. This could contribute to better health outcomes and/or to lower healthcare use, since health education may have a larger effect on the health-related behaviour of individuals with higher health literacy skills.

A systematic review shows that individuals’ health literacy skills can contribute to the explanation of the variation in health-related behaviour and health outcomes, such as perceived health status, hospitalizations, glycaemic control and vaccination or screening, in addition to other factors like education, sex, age and ethnicity. However, health literacy is relatively infrequently addressed in studies that address variation in health-related behaviour and health outcomes. Factors that are often addressed in this regard include individual characteristics such as ethnicity, sex, socio-economic position and age as well as psychosocial factors such as social support, motivation, beliefs/attitude, self-efficacy and knowledge. Therefore, health literacy seems to have an added value to other factors that are generally addressed when researchers attempt to explain variation in health-related behaviour and health.

Interest in health literacy is also prompted by its potential role in explaining health disparities. Health disparities are an important public health concern, even in countries with strong welfare systems such as the Netherlands. Studies indicate that health literacy can be considered as an underlying mechanism driving the relation between socio-economic position and health outcomes. Therefore, the WHO considers health literacy to be a central determinant of health inequalities and emphasizes the importance of research and initiatives to tackle the negative influence of lower health literacy on health outcomes.

**Conceptualization of health literacy**

Research on health literacy has emerged partly from the field of education in North America. Nationwide surveys of adult literacy conducted in the United States in the 1990s triggered interest in investigating literacy in the context of healthcare. Literacy encompasses the ability to read and write (basic literacy skills), but is also more broadly defined as the ability to use printed and written information in order to function in society, reach one’s goals and develop knowledge and opportunities. These nationwide literacy surveys have revealed
that those with the lowest literacy levels were also most likely to have the highest risk for health problems. During this period, the term health literacy became broadly adopted by public health theorists, originally defined as reading, writing and numeracy skills in the context of health and healthcare.

As the health literacy paradigm developed, it was noted that greater emphasis should be placed on health literacy beyond the medical setting, since health is constituted in daily life outside the consultation room or hospital. Furthermore, some commentators stated that the focus on reading and writing was too narrow and that individuals needed a wide range of cognitive and social skills to make best use of health systems. In this respect, Nutbeam’s typology of health literacy became influential since it conceptualized health literacy as advancing through levels of cognitive, inter-personal and social skills. This typology describes health literacy as consisting of three types: functional or basic health literacy, communicative or interactive health literacy and critical health literacy. According to Nutbeam, these three types of health literacy characterize the application of necessary skills for functioning effectively in everyday situations (functional health literacy), to more advanced literacy and cognitive skills that can be used to actively participate in everyday activities and apply new information to changing circumstances (interactive or communicative health literacy). At the top, health literacy extends to the even more advanced cognitive and social skills needed to critically analyse information, and use information to exert greater control over life events and situations (critical health literacy). In this typology, health literacy encompasses more than the ability to read information in print in a medical context, but also the ability to understand and react to verbal information, for example.

In addition to the three types of health literacy, Nutbeam also drew a distinction between two ways of approaching health literacy in research and practice, namely the ‘risk approach’ and the ‘asset approach’. The risk approach emerged from the perceived risk of low literacy for health outcomes. Research has implied that low literacy is associated with poorer health outcomes and higher healthcare costs, which has called attention to low literacy as a deficiency in the context of healthcare. The risk approach reflects the way health literacy is currently most often conceptualized in research stemming from clinical practice. Another perception of health literacy is as an asset—a means to exert greater control over health and over personal, social and environmental determinants of health. In this respect, health literacy is seen as an asset that can be developed instead of a deficiency. This ‘asset approach’ is more often adopted by public health researchers. Yet to date, most studies on health literacy have
focused on health literacy as a risk factor rather than an asset for health, although the latter approach to health literacy is gaining momentum.\textsuperscript{32,33}

Defining health literacy
As already indicated by the foregoing, the conceptualization of health literacy is not univocal and it is also subject to change.\textsuperscript{34} Over time, more than 17 definitions of health literacy have been suggested\textsuperscript{10} and the best way to define health literacy is still a topic of debate. For example, there is no agreement upon whether to include psychological factors such as knowledge and motivation as part of health literacy. Some scholars state that health literacy reflects skills, which can be learned and practiced and should not be entangled with psychological factors. Others find motivation a critical part of people’s ability to handle health-related information. Additionally, the discussion surrounding the conceptualization of health literacy is currently engaged with the question of whether or not context-specific literacies should be (further) distinguished (such as diabetes health literacy or media literacy) or whether a robust measurement of a general set of skills applicable in various health-related contexts should be the goal. Furthermore, there are deliberations on whether health literacy extends beyond individual skills and reflects the capacities of institutions or societies as well. This has led to terms such as ‘health-literate organizations’, which refers to organizations that make it easier for people to navigate, understand and use their services and information.\textsuperscript{35}

Measuring health literacy
Similar to the conceptualization of health literacy, the most appropriate way to measure health literacy is subject for discussion. Instruments that stem from a ‘risk’ perspective on health literacy were initially developed as screening instruments to be used by healthcare providers in clinical practice. These instruments are often applied to differentiate people with lower health literacy from those with higher health literacy. Such instruments are relatively short and focus on a quick identification of those who are likely to have lower health literacy skills. Examples are the Rapid Estimate of Adult Literacy, the Wide Range Achievement Test and the Test of Functional Health Literacy in Adults (see Table 1.1). Outcomes are often presented in quantitative terms (e.g., a certain number of people with low health literacy). Some of these instruments have also been validated and applied in questionnaire-based studies that aim to relate health literacy to health outcomes, such as the Set of Brief Screening Questions and the Newest Vital Sign (see Table 1.1). Instruments that stem from
an ‘asset’ point of view on health literacy have been developed to gain insight into the distribution and development of health literacy in the general population and appear to be more useful for application in public health. These types of instruments are extensive and generally provide a relative indication of health literacy (higher or lower scores). Examples are the European Health Literacy Survey Questionnaire, the Health Activities and Literacy Scale and the Health Literacy Questionnaire (see Table 1.1).

### Table 1.1 Health literacy instruments

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Instrument</th>
<th>What does it measure and how?</th>
<th>Context</th>
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<tbody>
<tr>
<td>Davis et al. (1991, 1993)</td>
<td>Rapid Estimate of Adult Literacy in Medicine (REALM)</td>
<td>Reading skills based on 125 words (long version) or 66 words (short version). Subjects are asked to read the words aloud and receive a score of one point per correctly pronounced word. Scores below 18 indicate that patients might not be able to read most low-literacy materials, scores between 19 and 44 indicate that patients need low-literacy materials, scores between 45 and 60 indicate that patients may have problems in reading most patient education materials, and scores above 60 indicate that patients are probably able to read most patient education materials.</td>
<td>Clinical practice</td>
</tr>
<tr>
<td>Parker et al. (1995)</td>
<td>Test of Functional Health Literacy in Adults (TOFHLA)</td>
<td>Reading comprehension, based on 50 items and numerical ability based on 17 items.</td>
<td>Clinical practice</td>
</tr>
<tr>
<td>Schwartz et al. (1997)</td>
<td>3-item numeracy measure</td>
<td>Health numeracy in the context of breast cancer screening, based on 3-items assessing familiarity with probabilities, converting percentages to proportions and proportions to percentages.</td>
<td>General population</td>
</tr>
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<tr>
<td>Lipkus et al. (2001)</td>
<td>10-item expanded numeracy scale</td>
<td>Health numeracy based on the 3 items as proposed by Schwartz and colleagues (1997) extended with 7 additional items assessing the extent to which people can differentiate and use percentages and proportions, convert percentages to proportions and proportions to percentages and convert probabilities to proportions.</td>
<td>General population</td>
</tr>
<tr>
<td>Chew et al. (2004)</td>
<td>Set of Brief Screening Questions (SBSQ)</td>
<td>Perceived difficulties with health information based on three 5-point Likert scale statements ranging from 0-4. An average score of ≤ 2 indicates inadequate health literacy, and a score of &gt;2 adequate health literacy.</td>
<td>Clinical practice</td>
</tr>
<tr>
<td>Rudd et al. (2004)</td>
<td>Health Activities and Literacy Scale (HALS)</td>
<td>Prose-, document and problem solving skills based on tasks that differ in complexity. Points ranges from 0 to 500 and are given for correctly fulfilling the task. More points were given for more complex tasks and less points for more simple tasks. An average score (ranging between 0 and 500) was calculated, with a cut-off scores for very poor health literacy, poor health literacy, adequate health literacy, high health literacy and very high health literacy.</td>
<td>General population</td>
</tr>
<tr>
<td>Weiss et al. (2005)</td>
<td>Newest Vital Sign (NVS)</td>
<td>Reading skills, numeracy skills and the ability to apply information based on six items concerning a nutrition label from an ice cream container. For each correctly answered one point is granted. A score between 0 and 1 suggests a likelihood of 50% of limited literacy, 2-3 indicates the possibility of limited literacy, and 4-6 almost always indicates adequate literacy.</td>
<td>Clinical practice</td>
</tr>
<tr>
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<td>Instrument</td>
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<td>Ishikawa et al. (2008)</td>
<td>Functional, Communicative and Critical Health Literacy measure (FCCHL)</td>
<td>Perceived functional, communicative and critical health literacy based on 14 statements using 4-point Likert scales from 1-4. Total scores are obtained by summing item scores and dividing by the total number of items.</td>
<td>Clinical practice</td>
</tr>
<tr>
<td>Lee et al. (2010)</td>
<td>Short Assessment of Health Literacy (SAHL)</td>
<td>18 items that reflect a word recognition test combined with a comprehension test with multiple-choice questions.</td>
<td>Clinical practice</td>
</tr>
<tr>
<td>Fullam et al. (2011)</td>
<td>European Health Literacy Survey Questionnaire (HLS-EU-Q)</td>
<td>Perceived difficulties with accessing, understanding, appraising and applying health related information concerning healthcare, disease prevention and health promotion. Based on 47 items (long version) or 16 items (short version) and 4-point Likert scale from 1-4.</td>
<td>General population</td>
</tr>
<tr>
<td>Osborne et al. (2013)</td>
<td>Health Literacy Questionnaire (HLQ)</td>
<td>Perceived functional, communicative and critical health literacy based on 44 items with 4-point or 5-point Likert scale options covering nine areas of health literacy.</td>
<td>General population and Clinical practice</td>
</tr>
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</table>

Instruments to measure health literacy can thus be categorized according to the perspective of health literacy that they are most closely serving. In addition, a distinction can be made between instruments that measure health literacy objectively and subjectively. Subjective measures provide an indication of the extent to which people feel they can understand and use health-related information. These instruments may also provide information on the demands of health systems, although, to date no instrument has been developed for this purpose. In addition to subjective measures, objective health literacy measures provide an indication of an individual’s literacy capability in the context of health derived by a careful examination of their ability to accomplish certain reading and problem-solving tasks. These are more closely related to the field of literacy research. Table 1.1 provides an overview of frequently applied health literacy measures, including the measures that were used in the present thesis.
(i.e., the Set of Brief Screening Questions; the Functional, Communicative and Critical Health Literacy measure; the Health Activities and Literacy Scale; the European Health Literacy Questionnaire).

Conceptual model of health literacy
The association between the performance on health literacy measures and health outcomes is indicated by a number of studies, but relatively little is known on processes through which health literacy affects health. In order to guide research on the relation between health literacy and health, Von Wagner and colleagues developed a conceptual model, see Figure 1.1, including key-elements of established psychological health-behaviour models.49 This model expands on the model developed by Paasche-Orlow and Wolf in 2007 50 and proposes that the association between health and health outcomes could be mediated by a range of health actions. The model makes explicit what factors are expected to constitute health literacy and via which routes health literacy is expected to affect health actions, which may subsequently determine health outcomes. Determinants of health literacy included in Von Wagners’ model are:

- Basic skills in reading and arithmetic. Being able to decode written text is considered a requirement for health literacy.

- Internal influences, which are thought to influence both the development as well as the maintenance of health literacy. Internal influences include cognitive abilities, age-related cognitive decline and pre-existing knowledge.51

- External influences, which are also thought to influence both the development and the maintenance of health literacy. External influences include the social environment (in particular parents), which plays an important role in acquiring language skills, formal educational opportunities and experiential learning. Experiential learning includes life events that increase exposure to (health-related) information, which can maintain or strengthen health literacy. This may include work, family or health-related events. However, little is known with respect to experiential learning throughout the life-course in relation to health literacy.

The model also focuses on the impact of health literacy on psychological determinants of health actions. To a large extent, the selection of these determinants is based on established theories and psychosocial models of health behaviour such as the Theory of Planned Behaviour and the Health Belief Model.53,54 These types of models share the idea that health actions result from a combination of motivational factors (e.g., knowledge and attitude) as well as
volitional factors (e.g., self-efficacy and planning skills). Various studies have underlined the association between health literacy and motivational factors, as well as self-efficacy.55 According to Von Wagner’s framework, these factors can be influenced by practical barriers (e.g., system characteristics or financial costs).49 In their paper, Von Wagner and colleagues further specify the psychological processes that are included in their model, describing that for instance preferences for emotional versus analytical information processing can also be placed under the denominator ‘attitudes’.49

Furthermore, they specify the volitional phase, by describing that this may include decision-making skills as well.49 Von Wagner and colleagues propose that health literacy can influence individuals’ decision-making process when deciding whether or not to perform a certain health action, like participation in cancer screening or vaccination. Furthermore, the researchers describe that in addition to these psychological factors, socio-economic and demographic determinants like gender and wealth are likely to be associated with both health actions and health literacy.49 These types of determinants were however not included in their conceptual model.

Last, the model outlines three types of health actions that can indirectly be influenced by health literacy. The first is the access and utilization of healthcare, the second is patient-provider interaction and the third is management of health and illness. Health literacy as a determinant of the utilization of healthcare is based on the finding that people with lower health literacy make more use of emergency care and hospital care, and make less use of preventive services (for instance, cancer screening).13 For example, less knowledge of screening possibilities or the severity of cancer, or a negative attitude towards screening could be a pathway between lower health literacy and lower cancer screening uptake. With respect to the second type of health action, patient-provider interaction, health literacy can have an important influence on the ability to interact with health-care providers. For instance, patients with lower health literacy may have more difficulty completing medical forms and asking relevant questions.56-58 The third type of action, management of health and illness, may include lifestyle-related behaviours as well as the performance of self-care tasks. Several studies indicate that lower health literacy is associated with a lower understanding of disease and treatment, lower adherence to medical instructions and lower self-managements skills.59
Figure 1.1 Conceptual model of determinants and consequences of health literacy by Von Wagner et al., 2009
Aim and research questions

To date, most studies on health literacy stem from North America and until recently, insights from European countries were lacking to a large extent. However, the importance of health literacy for public health is gradually being recognized in Europe. Little is known on the health literacy skills of general populations in relation to socio-economic and demographic characteristics, health actions and health-outcomes. Furthermore, most studies on health literacy have been conducted in the context of clinical practice, mainly among patients. An increased attempt is being made to foster individuals’ responsibility and autonomy, particularly with respect to chronic care and prevention. This makes it especially relevant to study the role of health literacy in the context of chronic care and prevention. Therefore, this thesis aims 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. Three research questions were formulated that could be placed in the conceptual framework of Von Wagner and colleagues. More specifically, the following three research questions were formulated:

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?

Outline of this thesis

In line with the three research questions, this thesis will be structured in three parts. Figure 1.2 illustrates the specific routes between health literacy and possible determinants, psychological factors, and health actions, that are presented in the present thesis. The numbers accompanying the arrows in this figure represent the chapter numbers in which the specific pathway will be the
focus of research.

**Part I – Health literacy in the Dutch adult population**
The objective of the first part of this thesis is to examine to what extent health literacy is related to socio-economic and demographic characteristics and health status in the Dutch adult population. The studies as described in this part of the thesis are driven by literature that suggests that health literacy relates to socio-economic and demographic characteristics as well as to health outcomes, rather than the conceptual model of Von Wagner and colleagues. Chapter 2 provides insight into the perceived health literacy skills of Dutch adults and the extent to which perceived health literacy skills relate to socio-economic position (indicated by level of education, income and perceived social status), age and gender. The findings as described in this chapter, are based on data from the European Health Literacy Survey (HLS-EU). Subsequently, Chapter 3 provides insight into the health literacy skills of the Dutch adult population based on an objective health literacy measure, namely the Health Activities and Literacy Scale (HALS). This chapter describes the extent to which health literacy relates to perceived general, mental and physical health and whether health literacy mediates the association between attained level of education and perceived general, mental and physical health.

**Part II – Health literacy in the context of chronic care**
The aim of the second part of this thesis is to obtain insight into the relation between health literacy and (psychological determinants of) use of primary care, patient-provider interaction and self-management in the context of chronic care. In this respect, Chapter 4 focusses on the relation between health literacy and diabetes self-management among patients with diabetes and explores the role of knowledge in this relation. The study described in this chapter is based on data that was obtained for the purpose of a larger observational study performed between January 2008 and June 2010 that focused on disease management programs and related bundled payments. Then, in Chapter 5 the relation between health literacy and perceived ability to exert control in healthcare is addressed, as indicated by perceived ability to exert control over the organization of care, interaction with health-care providers and self-care. Additionally, the relation between health literacy and the number of GP visits on a yearly basis is described. In this respect, attention is given to three types of health literacy: functional, interactive and critical health literacy. This study is based on data
form the ‘National Panel of people with Chronic illness or 107 Disability’ (NPCD), a Dutch nationwide prospective panel-study on the consequences of chronic illness or a long term disability.

**Part III – Health literacy in the context of prevention**

The aim of the third part of this thesis is to obtain insight into the relation between health literacy and psychological determinants of participation in prevention programs. More specifically, the chapters in this part of the thesis focus on decision-making with respect to cancer screening and preferences towards childhood vaccination. As expounded in the first paragraph of this general introduction, citizens are increasingly expected to be autonomous and responsible, including when it comes to the decision to participate in prevention programs. Whereas Dutch cancer screening campaigns used to be based on persuasive communication techniques, a shift has been made to an informed decision-making approach. This approach is based on the idea that in order to facilitate well-considered decisions, information on pros and cons should be provided. In the Netherlands, this approach is currently manifested with respect to the national colorectal cancer (CRC) screening program, which was introduced in 2014. In order to support the development of education materials on CRC screening, we aimed to provide insight into the current knowledge base on health literacy and informed decision-making on CRC screening. In this context, *Chapter 6* describes a systematic review of literature on the relation between health literacy and informed decision-making with respect to CRC screening. In this review it is examined in which aspects of the informed decision-making process individuals with lower health literacy differ from those with higher health literacy. Subsequently, this review examines whether health literacy is associated with the extent to which informed decisions are made. Then the last chapter of this thesis, *Chapter 7*, describes how health literacy relates to parents’ decisions to vaccinate their new-born against the rotavirus. By the use of a discrete choice experiment, whether parents with lower health literacy skills differ from parents with higher health literacy skills in their preferences for vaccine characteristics is explored. This study is part of a larger study investigating parental preferences for rotavirus vaccination.
Figure 1.2 Studied associations based on the conceptual framework of Von Wagner et al., 2009, including the chapter numbers in which the studied associations are described.
References


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