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## Health literacy and informed decision making regarding colorectal cancer screening: a systematic review

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### ABSTRACT

Making an informed decision about participation in colorectal cancer (CRC) screening may be challenging for invitees with lower health literacy skills. The aim of this systematic review is to explore to what extent the level of a person's health literacy is related to their informed decision making concerning CRC screening. We searched for peer-reviewed studies published between 1950 and May 2013 in MEDLINE, EMBASE, SciSearch and PsycINFO. Studies were included when health literacy was studied in relation to concepts underpinning informed decision making (awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation). The quality of the studies was determined and related to the study results. The search returned 2254 papers. Eight studies in total were included, among which seven focused on knowledge, four focused on attitudes or beliefs concerning CRC screening, and one focused on risk perception. The studies found either no association or a positive association between health literacy and concepts underpinning informed decision making. Some studies showed that higher health literacy was associated with more CRC screening knowledge and a more positive attitude toward CRC screening. The results of studies that obtained a lower quality score were no different than studies that obtained a higher quality score. In order to obtain more insight into the association between health literacy and informed decision making in CRC cancer screening, future research should study the multiple aspects of informed decision making in conjunction instead of single aspects.

### INTRODUCTION

Colorectal cancer (CRC) is one of the most common causes of cancer-related deaths worldwide.<sup>1</sup> As screening for CRC can identify precancerous polyps or cancers in their early stages, and thereby improve the survival rates of CRC, several countries have implemented national CRC screening programs.<sup>2-4</sup> Building on the idea of individual autonomy when making decisions about screening, it is increasingly being

recognized that screening programs should not aim to pursue screening invitees to participate. Instead screening programs should adopt an informed decision-making approach.<sup>5-8</sup> In accordance, invitees should receive information on CRC screening and the pros and cons of the screening program in such a way that enables them to make a well-informed decision whether or not to participate.

Informed decision making can be seen as a process that includes various stages (awareness, perception, evaluation and decision making) during which the gathering of information is an important element (see Supplementary figure S1).<sup>9</sup> During the first stage, the decision maker becomes aware of the issue about which a decision needs to be made. In the current context, this is CRC screening. During the second stage, the perceptions of CRC screening, for instance its pros and cons and the decision options (e.g. participate, not participate, participate in the future), are determined. The third stage refers to the evaluation of these decision options, including determining the utility of the decision options. In the last stage the decision is made based on the preceding stages.<sup>9</sup> An informed decision reflects the outcome of this process.<sup>10</sup> According to various definitions, a decision is considered to be informed when it is based on sufficient knowledge of the relevant aspects of the available alternatives and is consistent with the decision maker's values or attitude toward the issue at hand.<sup>10-12</sup> Van den Berg *et al.*<sup>10</sup> additionally included the evaluation of alternatives and the weighing up of their pros and cons (deliberation) as an indicator of an informed decision. This implies that in the context of CRC screening, an informed decision has been made when an invitee has sufficient knowledge concerning the consequences of CRC and the pros and cons of CRC screening, has deliberated about these pros and cons and has made a decision that is consistent with his or her attitude regarding CRC screening. So far, few studies have measured all of these aspects, but rather focus on one of these elements instead.<sup>13</sup> A distinction can thus be drawn between the process of informed decision making and informed decisions as an outcome of this process. Informed decision making, as well as indicators of informed decisions (knowledge, attitudes and deliberation about pros and cons), seem highly dependent on an individual's ability to understand and use information. Understanding and using information about CRC screening is challenging, especially for those who have difficulty comprehending health-related information.<sup>14</sup> Health literacy reflects the ability to access, understand, appraise and apply health-related information.<sup>15</sup> Since informed decision making is founded on the use of information, those with lower health literacy skills may be subordinated to those with higher health literacy skills when it comes to the opportunity to make an informed decision concerning participation in CRC screening. Studies indicate that individuals with lower health literacy skills are less familiar with cancer screening and have greater difficulties in making informed decisions about participation in cancer screening.<sup>16-20</sup> It is important that all invitees for CRC screening, including those with lower health literacy skills, make an informed decision whether or not to participate. This is important because individuals that make informed decisions have less decisional regret than those individuals whose decisions are not informed.<sup>9</sup> The aim of the present systematic review is to determine whether, and in what respect, health literacy is associated with informed decision making concerning CRC screening. More specifically, our objectives are to examine in which aspects of the informed decision-making process individuals with lower health literacy differ from those with higher health literacy. In addition our aim is to examine whether health

literacy is associated with the extent to which informed decisions are made. CRC screening uptake (isolated from informed decision making) will not be part of this review. A recent review already reflects on the association between health literacy and CRC screening uptake.<sup>21</sup> The result of this review can provide a knowledge base for the development of interventions in order to provide tailored support for individuals with lower health literacy in their CRC screening decision-making process. Furthermore, the results can indicate knowledge gaps in this area and provide direction for future research.

## **METHODS**

### **Search strategy and study selection**

We searched for original peer-reviewed studies on health literacy and informed decision making in CRC screening, published in English and Dutch between January 1950 and May 2013 in the following computerized bibliographic databases: MEDLINE, EMBASE, SciSearch and PsycINFO. The search strategy is included in table 1.

### **[TABLE 1]**

#### **Health literacy**

Health literacy is often defined as an individual's ability to access, understand, appraise and apply health-related information.<sup>15</sup> Studies that related one or more of these four elements to informed decision making or informed decisions were considered for inclusion. Studies were also considered for inclusion when health literacy was not explicitly defined as such (Sharma *et al.*<sup>22</sup> for example investigated whether trainees in internal medicine had adequate understanding of CRC screening). Additionally, studies that reported on health numeracy in relation to informed decision making in CRC screening were also considered for inclusion. Health numeracy is considered by some researchers to be an element of health literacy and reflects the ability to understand and use numerical health-related information, which is often part of risk communication.

#### **Informed decision making**

It was decided to adopt a broad approach to informed decision making by selecting studies that focused on (indicators of) the process of informed decision making or on (indicators of) informed decisions as the outcome of this process. The process of informed decision making included four stages: awareness of CRC screening; perception about CRC screening; evaluation of the decision options and decision making.<sup>9</sup> Informed decisions are generally characterized by knowledge, attitude-uptake consistency and deliberation.<sup>10,11,16</sup> Henceforth, the term 'informed decision making' will be used to refer to the process of informed decision making, as well as to informed decisions as an outcome. Studies that did not explicitly study informed decision making, but included, for example, knowledge as a single concept were still considered relevant for inclusion in the present review.

Pairs of researchers (I.v.d.H. and E.U. or M.F.) selected papers based on (i) the title, (ii) abstract and (iii) on the contents of full paper. Studies were excluded when: The role of health literacy or an element of health literacy (i.e. numeracy, accessing, understanding, appraising and applying)<sup>15</sup> was not studied in relation to informed

decision making (indicated by awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation or synonyms for these terms)<sup>9-11</sup> relating to CRC screening;

It was not an original peer-reviewed study;

The study was not performed in a Western country (as defined by Statistics Netherlands);

The study had no quantitative design.

#### [FIGURE 1]

##### **Data extraction and quality assessment**

After determining article inclusion, one reviewer (I.v.d.H.) extracted relevant data from all the included publications and a second reviewer checked the information for accuracy and completeness (E.U. or M.F.). Extracted data included the aim of the study, sample characteristics, measure of health literacy, measure of (an aspect of) informed decision making, context of CRC screening, statistical analyses and study results (see Supplementary table S1). Pairs of authors (I.v.d.H. and E.U. or M.F.) independently scored the quality of each study according to a selection of eight predefined criteria, as developed by the Dutch Cochrane Centre (23). Studies were scored based on the description of the sample characteristics and the data collection, the definition and operationalization of health literacy and informed decision making, and control for confounders (see table 2). In cases where reviewers disagreed about quality scores, consensus was achieved during a consensus meeting. The quality of the studies was used to interpret the study findings in light of their quality. The quality of each individual study was expressed by the number of criteria met. The score 'partly' was given when a criterion was partly met and counted as 0.5 when calculating the number of criteria met.

#### [TABLE 2]

## RESULTS

### **Included papers and characteristics**

Eight studies were included, of which the characteristics are described in Supplementary table S1. Five studies were carried out in the USA,<sup>24,27-30</sup> one in Japan,<sup>25</sup> one in Switzerland<sup>26</sup> and one in the UK.<sup>18</sup> The selection included one quasi-experimental design<sup>26</sup> and seven cross-sectional studies.<sup>18,24,25,27-30</sup> The aims of the studies are described in Supplementary table S1 as well as the type of CRC screening tests that were included in the studies (i.e. fecal occult blood test, flexible sigmoidoscopy and colonoscopy). All studies concentrated on single concepts related to informed decision making, including knowledge, attitude or beliefs, and the perception of risk information concerning CRC screening, instead of studying multiple concepts in coherence. No studies investigated health literacy in relation to attitude-uptake consistency or deliberation.

## **Findings on health literacy and concepts of informed decision making**

### **CRC (screening) knowledge**

Seven studies reported on the association between health literacy and CRC (screening) knowledge (Supplementary table S1).<sup>18,24,25,27-30</sup> Three studies assessed knowledge as indicated by the participants awareness of the possibility of CRC screening by ask respondents to name screening tests<sup>24,27,30</sup>; four studies applied more extended knowledge measures based on true or false statements.<sup>18,25,28,29</sup> Three studies found no association between health literacy and CRC (screening) knowledge.<sup>18,28,29</sup> Four studies implied that those with lower health literacy tend to have less knowledge regarding CRC screening, with the aside that different aspects of knowledge were measured (see Supplementary table S1).<sup>24,25,27,30</sup> Studies did not differ remarkably from one another when it came to the age and gender of the participants. The way in which health literacy was assessed may have partly contributed to the differences in the findings. Three of the four studies that found an association between health literacy and CRC knowledge applied the Rapid Estimate of Adult Literacy in Medicine (REALM) as a health literacy measure. Studies that did not find an association applied the Test of Functional Health Literacy in Adults (TOFHLA) or the REALM. The way knowledge was measured appears to have provided a more plausible explanation for the differences in study findings. Namely, studies that found an association applied more limited measures of knowledge that mainly assessed whether people had heard of CRC screening, knew screening was an option, or were able to name a screening test. These measures were mostly based on two to four items (leaving the study of Mitsutake aside).<sup>24,27,30</sup> The studies that did not find an association applied more extended measures of knowledge in the form of true–false questions based on 15–20 items.<sup>18,28</sup> This distinction between findings based on limited and more extended measures of knowledge, could imply that individuals with higher health literacy score just as bad on more complex knowledge as those with lower health literacy. The findings of two studies indeed indicate that CRC screening knowledge, assessed with a more extended measure of knowledge, is generally poor among those with higher and lower health literacy.<sup>18,29</sup> One other study indicates that CRC screening knowledge, assessed by a relative extended measure, is not that poor among those with higher and lower health literacy.<sup>28</sup>

### **Attitudes and beliefs**

Four studies reported on the association between health literacy and attitude and/or beliefs toward CRC screening (Supplementary table S1).<sup>24-27</sup> Two studies reported on attitudes and beliefs concerning CRC screening, without drawing a distinction between the two concepts, based on questions concerning perceived benefits, perceived barriers and perceived susceptibility toward CRC screening.<sup>29,30</sup> One study assessed beliefs and perceived barriers toward CRC (screening).<sup>24</sup> Another study measured CRC screening beliefs by assessing perceived benefits, barriers and perceived risk.<sup>28</sup>

These concepts were measured by various questionnaires (see Supplementary table S1). Since all of them reflected either beliefs, which can be seen as underpinning for attitudes,<sup>31</sup> or attitudes themselves, the findings were gathered under the current header of ‘attitudes and beliefs’.



The findings of the studies appear to be mixed. With respect to perceived barriers, two studies found no association with health literacy<sup>24,29</sup>, whereas two other studies found an association between health literacy and (part of) the included indicators of perceived barriers.<sup>28,30</sup> For instance, one study found that respondents with limited health literacy were more likely to believe that the Fecal Occult Blood Test (FOBT) was messy and inconvenient than those with adequate health literacy skills.<sup>30</sup> As to perceived benefits, two studies found no association with health literacy<sup>28,30</sup> as opposed to one other study.<sup>24</sup> The latter study found that individuals with low health literacy were less likely to believe that CRC screening would help to find colon and rectal problems early and thereby decrease the chances of dying from CRC as compared with those with adequate health literacy. With respect to perceived susceptibility to CRC, no association with health literacy was indicated by two studies.<sup>28,29</sup> whereas one other study did find an association.<sup>30</sup> More detailed information on the findings of the studies is reported in Supplementary table S1. Differences in findings were unlikely to be due to sample characteristics such as age and gender, which were quite similar between studies. Applied health literacy measures also seem unlikely explanations for the differences between study findings, as three studies applied the REALM<sup>24,28,30</sup> and one the TOFHLA.<sup>29</sup> What does differ between studies is the measure of attitudes and beliefs, and although the questionnaires show similarities, differences are also present. For instance, as opposed to other studies, Peterson *et al.*<sup>28</sup> included questions about costs as possible barrier.<sup>28</sup> And when it comes to perceived susceptibility, Dolan *et al.*<sup>30</sup> assessed whether respondents perceived their chances of CRC to be very high, whereas Guerra *et al.*<sup>29</sup> and Peterson *et al.*<sup>28</sup> assessed perceived susceptibility to CRC in comparison to age peers. Furthermore, a methodological difference between the studies is that Peterson *et al.*<sup>28</sup> calculated a mean score based on questions concerning barriers and benefits, whereas others studied each item separately.

### **Perception of risk information**

One study focused on risk perception by studying whether different presentations of risks concerning CRC were perceived differently by individuals with differing numeracy skills.<sup>26</sup> They concluded that different communication formats could lead to differences in risk perception, but that this was dependent on a person's numeracy skills.<sup>26</sup> Respondents with low numeracy skills perceived no difference in risk when high or low risks were presented, regardless of the format in which the risks were presented. Highly numerate respondents, on the other hand, reacted differently to higher risks and lower risks when they were presented in a Paling Perspective Scale, but not when they were presented as a ratio or a pictogram.

### **Methodological quality of the papers**

Table 2 summarizes the methodological quality of the included studies, which indicates that all studies clearly defined health literacy, as well as the informed decision-making concept(s) included in the particular study. Health literacy was considered to be clearly defined when the researchers provided either a definition of health literacy or described what was considered to be higher or lower health literacy in light of the applied instrument. All of the included studies applied a validated measure of health literacy. Most studies applied the REALM to assess health literacy.<sup>24,27,28,30</sup> Other instruments included the TOFHLA,<sup>18,29</sup> the J-eHEALS (for e-health literacy)<sup>28</sup> and the Lipkus scale (for health numeracy).<sup>26</sup> Five studies described

that health literacy was administered verbally,<sup>24,26,28-30</sup> which is relevant because those with lower health literacy may perceive answering written questions to be more difficult. As to the informed decision-making aspects, table 2 shows that two studies described that a validated instrument was applied to assess knowledge, attitude and beliefs.<sup>24,28</sup> Two other studies provided a description of how an instrument to assess knowledge, attitudes and beliefs concerning CRC screening was carefully designed, including testing the understandability of the instrument and pilot testing the instrument.<sup>29,30</sup> Seven studies controlled for relevant confounders in the design or in the analyses (including at least an indication of socio-economic status (SES), ethnicity and age).<sup>18,24,25,27-30</sup> Concerning the sample selection and description, five studies obtained the score 'partly' because either the method of recruitment,<sup>18</sup> the ethnic background of the sample,<sup>25</sup> the geographic location<sup>27</sup> or the period<sup>26,29</sup> was unclear. All studies provided insufficient information concerning the original population. The quality per study ranged from 3 (Ref. 26) to 7 (Ref. 28) out of 8 points possible (see table 2). Differences in study findings are unlikely to be due to the quality of the studies, as quality scores were relatively high overall and no remarkable differences in study findings were detected when comparing studies of lower quality with studies of higher quality (see table 2).

## DISCUSSION

### Discussion of main findings

The results of the present review indicate that the body of literature on the association between health literacy and informed decision making concerning CRC screening is limited. Studies included in this review focused on individual concepts underpinning informed decision making, including knowledge, attitudes or beliefs, and risk information perception rather than focusing on multiple indicators of informed decisions or on multiple stages of the process of informed decision making. Most of the included studies presented either no association between health literacy and these concepts or an association in the expected direction, namely lower health literacy was associated with less knowledge or a less positive attitude toward CRC screening. No consistent pattern was found with respect to study findings and study quality; both studies of higher and lower quality showed no association or an association as expected. The most frequently studied concept of informed decision making was CRC screening knowledge, which was the subject of seven studies. Four of these studies indicated that those with lower health literacy have less CRC screening knowledge. Furthermore, four studies reported on the association between health literacy and attitudes and beliefs and showed varying results. A single study reported on the perception of risk information according to health literacy. The focus on knowledge is a deficiency of the current theory base, because knowledge is not the only determinant in the decision as to whether or not to participate in CRC screening.

The studies included in this review stemmed from various countries in which CRC screening is organized differently. Both USA and Switzerland offer organized as well as opportunistic CRC screening, depending on the region, whereas Japan and the UK have organized national screening programs.<sup>4</sup> The way CRC screening is organized may influence the extent to which people are aware and knowledgeable about CRC screening. However, we were unable to link CRC screening organization

to the study findings, as most of the studies stemmed from USA with single studies coming from the UK, Switzerland and Japan.

Studies applied various measures of functional health literacy. Furthermore, the studies included in the present review measured various aspects of knowledge and attitudes. When it comes to knowledge, some operationalizations reflected familiarity with or awareness of CRC screening,<sup>30</sup> whereas other operationalizations were more in-depth and included rather complex (true/false) knowledge questions like, ‘About one in 20 people in the UK develop bowel cancer during their lifetime’.<sup>18</sup>

Differences in CRC screening knowledge between those with lower and higher health literacy skills seemed present less often when studies applied more extended measures of CRC screening knowledge.<sup>17,32,33</sup> The heterogeneity in the operationalizations of both health literacy and concepts underpinning informed decision made it more difficult to obtain a clear insight into the relation between health literacy and informed decision making. Furthermore, the methodological distinction between concepts was sometimes unclear; the questions studied applied to assess attitudes or beliefs were in some cases difficult to disentangle from knowledge questions. Nevertheless, this review provides indications that informed decision making may be more complicated for those with lower health literacy skills than for those with higher health literacy skills.

Reflection on knowledge and decision making

Informed decision making is based on the assumption that during the decision-making process information regarding the issue at hand is gathered and used (see Supplementary figure S1). A possible explanation for the finding indicating that those with lower health literacy are less knowledgeable concerning CRC screening as compared with those with higher health literacy is that those with lower health literacy may have had less exposure to information on CRC screening. Individuals with lower health literacy have, for instance, been found to be less likely to seek out information, less likely to utilize health information resources and have reported a lower frequency in reading and computer use than those with higher health literacy.<sup>17,18,34</sup> Subsequently, individuals with lower health literacy seem more likely to avoid information about diseases they do not have and to seek information about cancer prevention or screening from a health care professional instead of turning to the Internet.<sup>17</sup> This implies that before receiving an invitation, those with higher health literacy are more likely to have thought about screening and have perhaps already formed an opinion concerning screening than those with lower health literacy. It is also possible that individuals with higher health literacy are more likely to have discussed the pros and cons of screening with relatives, friends or colleagues than those with lower health literacy, which leads to a more reasonable and informed initial opinion regarding CRC screening upfront.<sup>35,36</sup> This assumption is supported by the conceptualization of health literacy by Nutbeam, in which the ability to interact with others on health-related issues (interactive health literacy) is considered a key aspect of health literacy.<sup>37</sup> Among the studies that were included in this review, no study investigated the association between interactive health literacy and informed decision making. Differences in exposure to CRC (screening) information as well as in interaction on CRC (screening) with others could influence the way information concerning CRC screening is perceived and evaluated. This reflects the second and third stage of the process of informed decision making and may thereby affect the fourth stage of the process, namely the decision that is made.



### **Reflection on measuring health literacy**

All of the studies included in the present review operationalized health literacy as functional health literacy. Being functionally health literate means being able to read and understand basic health-related information, including an invitation for screening. However, health literacy entails the ability to judge, discuss and apply information to one's situation as well. These types of skills are also referred to as interactive and critical health literacy,<sup>37</sup> which are relevant when it comes to decision making concerning CRC screening.<sup>38</sup> It is therefore important that future research addressing health literacy in relationship to informed decision making applies a health literacy measure that includes interactive and critical skills as well. As Smith and Nutbeam demonstrate, functional, interactive and critical health literacy have different roles in the process of decision making for CRC screening.<sup>38</sup> Research that reflects on multiple aspects in relation to CRC screening decision making, can better inform the type of initiatives that could support informed decision making, than research that reflects merely on functional health literacy.

### **Implications**

We formulated implications with respect to the conceptualization of informed decisions, the measurement of CRC (screening) knowledge and the inclusion of deliberation in future research. The idea behind informed decisions is that a person's autonomy is respected and that invitees do not feel coerced into or deterred from participating in CRC screening. It seems however important to consider whether the conceptualization of informed decisions in the literature to date is feasible or suitable for CRC screening in general and for screening invitees with low health literacy in particular. Namely, informed decisions conceptualized as a combination of sufficient knowledge, deliberation of pros and cons, and a decision that is consistent with personal values assumes that invitees are rational decision makers that apply analytical decision-making strategies. Analytical decision making is most likely to occur in a situation that is characterized by clear pros and cons, when deciding on a healthcare insurance for example. However, when it comes to CRC screening, pros and cons are difficult to weigh and decisions are very likely to be influenced by emotions or social influences.<sup>9</sup> The operationalization of informed decisions in screening research often does no justice to the way in which people make decisions in their daily lives and may therefore need to be reconsidered. For instance, studies could assess (qualitatively) whether invitees have the feeling that the decisions they make are sufficiently informed.

Furthermore, we found that knowledge is relatively often studied in relation to health literacy and CRC screening, but that studies apply various measures of knowledge. We suggest that because knowledge is considered a prerequisite for informed decision making, it is essential to gain a better understanding of what knowledge is crucial in making informed decisions, and whether the amount or type of knowledge needed to make informed decisions differs according to one's health literacy skills. Based on previous studies, which indicate that individuals with lower health literacy are less likely to seek information concerning CRC screening when compared with those with higher health literacy, it seems likely that those with higher health literacy may prefer more information, whereas those with lower health literacy may prefer less or different information. It is possible that a distinction could be made between basic knowledge, such as knowing what CRC screening is and how screening can help prevent CRC<sup>28</sup> and advanced knowledge, such as knowing the pros and cons of

participation in CRC screening. Further deliberation is needed to determine what basic knowledge and more advanced knowledge should entail and what people should really know as a minimum in order to make informed decisions. For instance, because people often have difficulties understanding the idea of informed decision making explaining the concept of informed decisions could be considered essential information that everyone should receive, as opposed to encouraging screening participation.<sup>20</sup>

Further research should also be undertaken to determine differences in information needs between those with lower and higher health literacy concerning CRC screening, whether various standards should be used in order to determine when a decision can be considered informed for different people, and who should determine these standards. When we have identified the knowledge that is essential and how we should assess this, then the development of effective interventions to facilitate informed decision making for people with varying levels of health literacy will be possible.

Third, no study was found that focused on the process of deliberation in relation to health literacy and CRC screening. Future research may want to focus more on this aspect of informed decision making, as this may be difficult for both those with higher and lower health literacy. In this context, it is relevant to explore whether people with higher health literacy are more likely to discuss the option of CRC screening with friends and family as compared with people with lower health literacy and whether talking about CRC screening in the lay network influences the decision-making process. This would provide us with insights into whether stimulating talking about CRC screening would facilitate informed decisions. More (qualitative) research should be carried out to evaluate in which ways people would like to be supported in their decision making concerning CRC screening participation.

## CONCLUSION

It can be concluded that there is either no association or a positive association between health literacy and concepts underpinning informed decision making, including knowledge and attitudes. The present review indicates that studies to date mainly focus on single aspects of informed decision making, instead of a combination of aspects. Although this provides valuable insights, a more comprehensive examination of informed decision making in which aspects are studied in conjunction may provide additional insights into how health literacy relates to informed decision making. A future direction for research would be to obtain a better understanding of what informed decision making should encompass in the context of CRC screening and to what extent this may differ according to an invitee's health literacy skills.

## Supplementary data

Supplementary data are available at *EURPUB* online.

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*Conflicts of interest*: None declared.

## KEY POINTS

- The body of literature on the association between health literacy and informed decision making concerning CRC screening is limited.
- Studies included in this systematic review focus on single concepts underpinning informed decision making (i.e. knowledge, attitudes or beliefs and risk information perception) rather than on multiple indicators of informed decisions or on multiple stages of the informed decision-making process.
- Studies show varying results with most studies presenting either no association between health literacy and concepts underpinning informed decision making, or an association in the expected direction, that is lower health literacy is associated with less knowledge or a less positive attitude toward CRC screening.
- This review implies that future research should focus on obtaining a better understanding of what informed decision making in the context of colorectal screening should encompass in relation to health literacy.

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## TABLES AND FIGURE

**Table 1** Search strategies used in MEDLINE (this search was adapted to be used in EMBASE, SciSearch and PsycINFO)

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### Search strategy in MEDLINE

- 1 (colorectal cancer or colon\* cancer or colorectal neoplasms or crc or colon\* neoplasms or bowel cancer or bowel neoplasms).ti.
  - 2 exp colorectal neoplasms/ or exp colonic neoplasms/ or rectal neoplasms/
  - 3 1 or 2
  - 4 screening.ti. or mass screening/ or early detection of cancer/ or early diagnosis/ or population surveillance/
  - 5 (fecal occult blood test\* or faecal occult blood test\* or stool guaiac test\* or fobt or gfovt or ifobt or fecal immunochemical test\* or faecal immunochemical test\* or fecal dna test\* or faecal dna test\* or double contrast barium or dcbe or bariujm x-ray or colonoscop\* or sigmoidoscop\* or colonograph\* or digital rectal).ti.
  - 6 fit.ti. and immunochemical.ab.
  - 7 colonoscopy/ or sigmoidoscopy/ or digital rectal examination/ or colonography, computed tomographi/
  - 8 4 or 5 or 6 or 7
  - 9 (literacy or literate or numeracy or education or evidence based risk information or evidence based information or informed choice\* or informed decision\* or shared decision making or shared-decision making or knowledge or cognitive ability or (retention adj5 information) or (recall adj5 information) or information processing or 'ability to seek' or information seeking or self-efficacy or perceive confidence or comprehension or understanding or 'locus of control' or adequate information or inadequate information).ti.
  - 10 \*health education/ or \*educational status/ or \*health knowledge, attitudes, practice'/ or \*health literacy/ or \*self-efficacy/ or \*informed consent/ or \*educational measurement/
  - 11 \*mental processes/ or \*cognition/ or \*comprehension/
  - 12 (attitude\* or acceptance or acceptability or willingness or unwilling\* or hesitant or hesitate or motivation or intention\* or belief\* or opinion\* or views or standpoint or preference\* or prefers or refusal or adherence or delay or perceived benefits or barrier\* or anxiety or fear or concern\* or perception\* or decision\* or decided or deliberation\* or considerations or decision making or attitude-uptake consistency).ti.
  - 13 (debate or discussion\* or awareness or eligibility or intention\* or initiation or preference\* or compliance or behavior\* or choice or choose or reason\* or consent).ti.
  - 14 \*attitude/ or \*attitude to health/ or \*\*patient acceptance of health care'/ or \*retention/ or \*choice behavior/ or \*decision making/
  - 15 (risk information or communication or communicating or risk presentation or leaflet\* or pamphlet\* or notification or pre-notification or promot\* or intervention\* or readability or effective health promotion or (source\* adj4 information) or decision aid or decision support or influencing factors).ti.
  - 16 \*communication/ or \*health communication/ or \*communication barriers/ or \*information systems/ or \*decision making/ or \*decision support techniques/ or \*pamphlets/ or \*\*patient education as topic'/ or \*information services/
  - 17 (media or internet or website\* or 'social networking' or social networks or message\* or media campaign or informatics).ti.
  - 18 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
  - 19 3 and 8 and 18
  - 20 19 and (english or dutch).lg.
  - 23 remove duplicates from 19
-



Figure 1: Flow diagram literature search

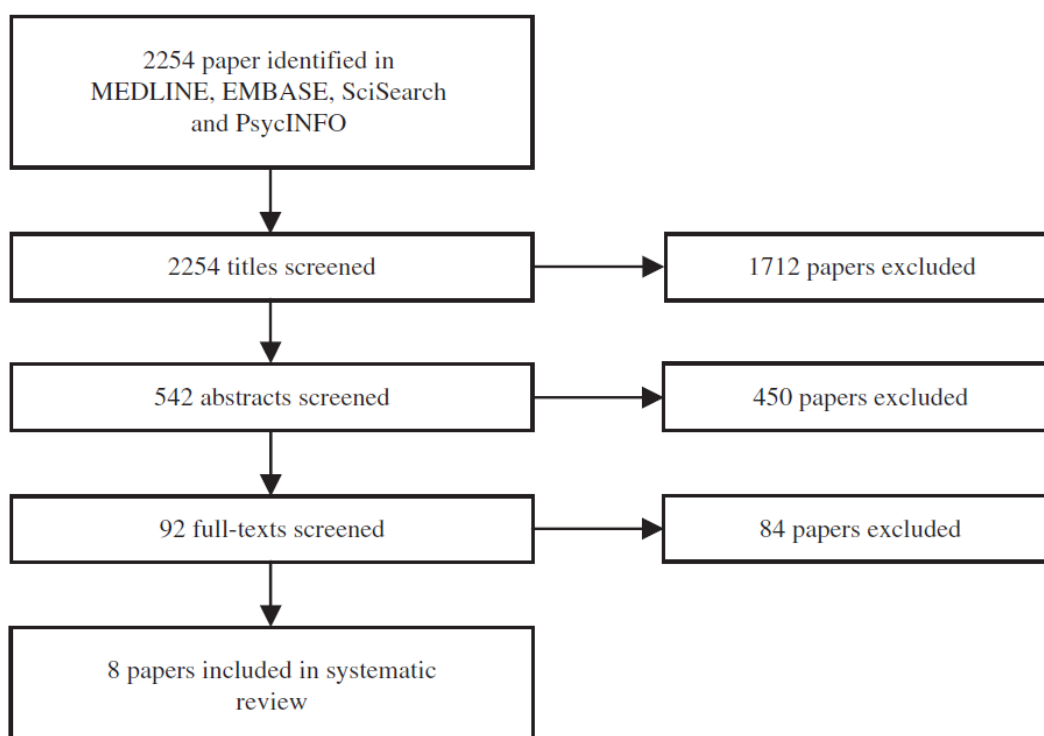


Table 2 Studies (n=8) meeting the quality criteria<sup>23</sup>

Criteria	Studies meeting the criteria								Total number of studies meeting the criteria (partly)
	Arnold et al. <sup>24</sup>	Mitsutake et al. <sup>25</sup>	Von Wagner et al. <sup>18</sup>	Keller et al. <sup>26</sup>	Miller et al. <sup>27</sup>	Peterson et al. <sup>28</sup>	Guerra et al. <sup>29</sup>	Dolan et al. <sup>30</sup>	
1. The study population and the recruitment method were clearly described <sup>a</sup>	1	0.5	0.5	0.5	0.5	1	0.5	1	3(5)
2. The original population was clearly described.	0	1	0	1	1	1	1	1	6
3. The study population was an adequate reflection of the original population.	0	0	0	0	0	0	0	0	0 <sup>b</sup>
4. Health literacy was clearly defined.	1	1	0	1	1	1	1	1	7
5. Health literacy was assessed by a validated instrument.	1	1	1	1	1	1	1	1	8
6. The outcome measure was clearly defined.	1	1	1	1	1	1	1	1	8
7. The outcome measure was assessed by a validated instrument.	1	0	0	0	0	1	0.5	0.5	2 (2) <sup>c</sup>
8. Important confounders taken into account in the analyses or in the research design. (SES, age, ethnicity and sex.)	1	0.5	1	0	1	1	1	1	6 (1)
Total number of criteria met per study	6	5	3.5	4.5	5.5	7	6	6.5	-

<sup>a</sup>Information was given on sample size, age, gender, SES, ethnicity, study setting, geographic location, timeframe and method of recruitment.; <sup>b</sup>None of the included studies provided sufficient information regarding this criterion; <sup>c</sup>Studies that partly met this criterion did not apply a validated instrument but the instrument was carefully designed and described.