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**Title:** Empirical relationships between health literacy and treatment decision making: A scoping review of the literature

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## **Abstract**

**Objectives:** This study asked: What is known from the existing literature about the empirical relationships between health literacy (HL) and the three stages of the treatment decision making (TDM) process: information exchange, deliberation, and deciding on the treatment to implement?

**Methods:** A scoping review of the literature was conducted. Four databases were searched and a total of 2,772 records were returned. After de-duplication and three levels of relevance screening, 41 primary studies were included.

**Results:** Relationships between HL and information exchange were studied more often than relationships between HL and deliberation and deciding on the treatment to implement. Across the 41 studies, there was little overlap in terms the measure(s) of HL adopted, the aspect of TDM considered, and the characteristics of the study populations – making comparisons of the findings difficult. Multiple knowledge gaps and measurement-related problems were identified; including, the possibility that the process of TDM influences HL.

**Conclusion:** The importance of HL to the three stages of TDM is unclear because of the knowledge gaps and measurement-related problems that exist.

**Practice Implications:** There are many uncertainties about how TDM, or the design and use of patient decision aids, should respond to patients with different levels of HL.

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## 1.0 Background

Internationally, there has been a growing trend toward the implementation and, in some cases legislation, of shared decision making (SDM) in the clinical encounter [1,2]. Although the term SDM has been variously defined, one of the key features of SDM is that both physicians and patients “take steps to participate in the process of treatment decision-making” [3<sup>(p686)</sup>].

Related to the movement to implement SDM, is a growing international movement to promote the implementation of patient decisions aids (PDAs) in clinical practice [2]. PDAs have been defined by the International Patient Decision Aid Standards Collaboration [4<sup>(para1)</sup>] as, “tools designed to help people participate in decision making about health care options. They provide information on the options and help patients clarify and communicate the personal value they associate with different features of the options”.

Relevant to the shift to implement SDM and PDAs in clinical practice, is the notion that health literacy (HL) is important to treatment decision making (TDM). Claims to support this notion can be found in statements made in the academic literature; for example: “health literacy is *required* for patients to *effectively use decision aids*” [5<sup>(p2)</sup>]; “health literacy is a *prerequisite* for *informed health care decision making*” [6<sup>(p1)</sup>]; and “[I]mproving health literacy has the

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*potential to promote*", among other things, "*more informed decision making*" [7<sup>(p200)</sup>]. These statements generally imply that HL influences TDM.

Reflecting and/or reinforcing the notion that HL is important to TDM are provisions found within the 2010 U.S. Patient Protection and Affordable Care Act (ACA). Section 936, which is titled "Program to Facilitate Shared Decisionmaking", includes provisions supporting the development, updating, and production of PDAs that "present up-to-date clinical evidence about the risks and benefits of treatment options" in a manner that, among other things, "reflects the varying needs of consumers and diverse levels of *health literacy*" [8<sup>(p1090)</sup>]. Implied in these provisions is the notion that people with different levels of HL have different needs that should be respected with regard to the way that information about treatment options and their risks and benefits are presented in PDAs. That is, a particular PDA developed for patients with a high level of HL may not meet the needs of patients with a low level of HL.

Ethical arguments for enabling people to participate in decision making about their treatment are now widely accepted. However, many uncertainties remain about how this is best done, in part because of uncertainties about relationships between HL and TDM [9, 10]. Policy initiatives, such as the 2010 U. S. ACA, make it particularly important to attend to these uncertainties. In this study we sought to answer: *What is known from the existing literature about the empirical relationship(s) between HL and TDM?*

## **2.0 Methods**

### *2.1 Research design*

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A scoping review of the literature was undertaken using the approach described by Arksey and O'Malley [11]. Scoping reviews allow researchers to: (1) examine, or map, the extent, range, and nature of research activity in a topic area of interest; (2) "identify gaps in the existing literature"; and (3) "determine the value of undertaking a full systematic review" [11<sup>(p.21)</sup>]. In the adopted approach, five stages are outlined. A description of how these five stages were applied in this review follows.

## *2.2. Identification of the scoping review question (Stage 1)*

To allow for a broad and inclusive approach to the topic of interest, the Charles et al. [3] TDM framework was also adopted in this study. In this framework, different approaches to TDM (i.e., informed, shared, paternalistic) are described as well as three analytic stages that are common to each of the different approaches (i.e., information exchange, deliberation, deciding on the treatment to implement). To reflect this conceptualization of TDM, the research question was adjusted to: *What is known from the existing literature about the empirical relationship(s) between HL and the three stages of the TDM process?*

## *2.3 Identification of relevant studies (Stage 2)*

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To identify relevant studies, a literature search strategy for the four electronic databases listed in Table 1 was developed in consultation with a specialist librarian. Terms relating to health literacy and to treatment decision making (including physician-patient communication) were identified for each data base. The search terms and combinations used in each database can be found in Appendices A through D.

### ***Insert Table 1***

As shown in Figure 1, a total of 2,772 records were retrieved from the four databases. A search of the reference lists of all review papers (n=83) did not lead to the identification of any new records. After de-duplication, 2,023 records remained and were uploaded into Distiller SR © for relevance screening.

### ***2.4 Study selection (Stage 3)***

Two levels of relevance screening criteria were developed, agreed upon, and pre-tested on a small sub-set of records by all of the authors. The first level of relevance screening (RS1) criterion was applied to the title and abstracts of all remaining records by LMW and MW. Records remaining after RS1 were read in full by LMW and MW to determine whether or not they met the second level (RS2) of inclusion criterion. Following RS2, a decision was made to exclude studies that did not explicitly mention the term HL, or assess HL (i.e., those that examined vision-related reading ability, literacy, or numeracy). This decision was made given:

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(1) that HL was one of the key terms in our scoping review question, and (2) the limited time and resources available to conduct this review. The exclusion of these studies was done through the application of a third level of relevance screening criterion (RS3). The entire relevance screening process is depicted in Figure 1. Any conflicts arising during this process were discussed and resolved by the LMW and MW and/or the research team.

### ***Insert Figure 1***

#### *2.5 Charting the data (Stage 4)*

A data charting form (DCF) was developed and pre-tested independently by LMW and CAC on a small subset of studies. After pre-testing, LMW applied the DCF to the remainder of the studies. The following information was charted, if provided: author(s), publication date, location; intervention type, and comparator; characteristics of the study populations; study aims; methodology; outcome measures; and results relevant for answering the scoping review question. Any definition(s) of HL adopted, the instrument(s) used to assess HL, the type(s) of TDM approaches examined, and the stage(s) of TDM examined were also charted.

#### *2.6 Collating, summarizing, and reporting the results (Stage 5)*

In the sections that follow, a narrative account is provided of the temporal and geographical distribution of the 41 studies included in this review; the research designs and study populations used; and the definitions and measures of HL adopted by researchers. The empirical

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relationships relevant for answering the research question are then reported and thematically organized according to their relevance to the three stages of TDM. Quality appraisal of studies is not an integral part of the adopted scoping review method [11]; however, the limitations in the methods used, and the gaps in the existing literature, are noted as well as their implications for research, policy, and practice.

### **3.0 Results**

#### *3.1 Temporal and geographical distribution of the 41 studies*

Forty of the 41 studies included in the review were published after the year 2001, with the majority (n = 31) being published in the years between 2009 and 2013. Thirty-four studies were conducted in the U.S. Two studies were conducted in Australia. Only one study was conducted in each of the following countries: U.K., Germany, Japan, Taiwan, and the Netherlands.

#### *3.2 Research designs and study populations*

Cross-sectional correlational studies (n = 18) were the most prevalent, followed by experimental or quasi-experimental (n =10), qualitative (n =9), and mixed-methods (n = 4) studies. Across studies, the number, socio-demographic characteristics, and health status, of the patients recruited varied. Patients diagnosed with cancer, or at risk for developing cancer, were

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the patient group most commonly focused on. Patients who were White, female, English-speaking, 50 years of age and older, and more health literate (as deemed by the authors) featured more often in study samples than their non-White, male, non-English-speaking, younger and less health literate counterparts.

### *3.3 Definitions and measures of HL*

Twenty-one studies provided one or more definitions of HL. These definitions are listed in column three of Tables 2 through 4. Ratzan and Parker's [12] definition of HL appeared in 14 studies. Ratzan and Parker[12<sup>(pxi)</sup>] define HL as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions". The remaining studies provided different definitions of HL. Two studies provided multiple definitions of HL.

The measures of HL adopted in studies are listed in column four of Tables 2 through 4. The Rapid Estimate of Adult Literacy in Medicine (REALM), or a shortened, modified, or translated version of the REALM, was the most commonly used in studies. This "is a screening instrument to assess an adult patient's ability to read [or pronounce] common medical words and lay terms for body parts and illnesses" [13<sup>(para1)</sup>].

Three studies used the Test of Functional HL in Adults (or TOFHLA), eight used the shortened version (or S-TOFHLA), and five used a Spanish version. The TOFHLA is a timed test of reading comprehension of passages taken from "instructions for preparation for an upper gastrointestinal series, the patient rights and responsibilities section of a Medicaid application form, and a standard hospital consent form" [21<sup>(p538)</sup>]. Six studies used measures of HL other

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than the REALM or TOFHLA (or S-TOFHLA) [16,18,28,30,31,32] . Five studies used more than one measure of HL [16,18,22,28,30].

A comparison of the definitions and measures of HL listed in columns 3 and 4 of Tables 2 through 4 reveals the following. First, some of the constructs assessed by measures of HL were not fully, or even partially (in some cases), congruent with the underlying components of definitions of HL provided by authors in their studies. To illustrate, Ratzan and Parker's [12<sup>(pxi)</sup>] definition of HL - "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" - was matched most commonly with the REALM which assesses a person's ability to pronounce medical terms.

Second, some measures of HL focused on a single dimension (e.g., pronunciation, level of education), rather than recognizing the multidimensional nature of HL. Third, some measures of HL were used in an inconsistent manner across studies, making comparisons of the findings difficult. For example, the original four categories of the REALM (i.e., 0-3<sup>rd</sup> grade, 4<sup>th</sup> -6<sup>th</sup> grade, 7<sup>th</sup>-8<sup>th</sup> grade, 9<sup>th</sup> grade and above) were used in some studies [22,33,34,35,36,37], but were reduced to three [38,39,40,41] or two [14,15,42,43,44,45,46,47] in others – with some loss of information and thus implications for the validity of the findings. In two studies, the REALM was treated as a continuous variable [16,48]. In another study, the authors [22] reported variation between the scores obtained on the REALM and the S-TOFHLA - raising questions about whether or not these instruments are measuring the same construct. All of these issues

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suggest caution when attempting to compare estimates of HL and interpret findings across studies.

### *3.4 Empirical relationships examined between HL and the three stages of the TDM process*

Tables 2 through 4 present the findings according to their relevance to the three stages of the TDM process. The majority of studies (n = 27) examined relationships relevant only to the first (information exchange) stage of the TDM process (see Table 2). Eleven studies examined relationships relevant only to the second (deliberation) stage (see Table 3). Ten studies examined relationships relevant only to the third (deciding on the treatment to implement) stage (see Table 4). Five studies [18,24,25,43,45] examined relationships relevant to both stages 1 and 2. Two studies [9,26] examined relationships relevant to both stages 1 and 3. One study [46] examined relationships relevant to all three stages. In the sections that follow, the main findings from Tables 2 through 4 are summarized. Unique or unexpected findings are identified with an asterisk (\*) in the Tables.

#### *3.4.1 Findings relevant to the information exchange stage of the TDM process*

In the Charles et al. [3] TDM framework, information exchange can occur at any time throughout the medical encounter. Findings relating to relationships between HL and the type, amount, and flow of information that is exchanged between a physician and patient are listed in Table 2.

Seven studies reported on relationships between measures of patients' HL and different variables relating to patients': desire for information [34,45,42]; informational needs regarding

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disease, diagnostic tests, treatment, self-care, etc. [22]; question asking [30,43]; and information seeking habits [18]. In three of these five studies, no relationships were observed [22,34,45]. In the remaining studies, the findings were variable.

Three studies examined empirical relationships between patients' scores on one or measures of HL and patients' knowledge about prostate cancer [48] hormone therapy [24]; and pelvic floor disorders [25]. In two of these studies, positive relationships were observed between patients' HL scores and patients' knowledge scores [24,48]. In the remaining study, Spanish-speaking patients lacked knowledge about their condition irrespective of their HL score. Ten studies examined empirical relationships between assessments of patients' HL and patients' understanding of information [9,14,15,17,19,23,33,35,50,51]. Across these studies, patients' understanding was variously defined and measured by researchers and the findings were also variable.

Two studies examined relationships between measures of patients' HL and: (1) the amount of counseling and direction provided by physicians to patients [30], and (2) physicians' use of unclarified medical jargon when communicating with patients [23]. Across these studies, the findings were variable. Another five studies investigated relationships between measures of patients' HL and patients' assessments of their health care providers' communication [16,26,36,46,47]. Across these studies, the findings were variable and, in some cases, contradictory.

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## ***Insert Table 2***

### *3.4.2 Findings relevant to the deliberation stage of the TDM process*

Deliberation is “the process of expressing and discussing treatment preferences” and, depending on the TDM approach adopted, can include the physician, the physician and the patient, or the patient alone [3<sup>(p656)</sup>]. Column five of Table 3 lists the empirical relationships that have relevance to the deliberation stage.

Eleven studies examined empirical relationships between assessments of patients' HL and patients' (or informal caregivers') perceptions about participation or involvement in decision making [18,20,24,25,27,28,43,37,45,46,52]. Across these studies, the findings were variable, and higher assessments of patients' HL were not always positively associated with patients' desired or perceived level of participation or involvement in deliberation.

In regards to the measurement of participation, or involvement, it is important to note that, in one study, the authors reported that their measure of participation had not been validated for use in their study [20]. The quantitative measures used to assess participation, or involvement, also relied on self-report data from participants, which, as some researchers noted, is susceptible to recall [53] and social desirability [54] response bias.

## ***Insert Table 3***

### *3.4.3 Findings relevant to the deciding on the treatment to implement stage of the TDM process*

The decision on the treatment to implement refers to the process of selecting a specific treatment option to implement from the range of treatment options presented, and clarifying the

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respective roles of the physicians and patients in this process [3]. The empirical relationships that have relevance this stage are listed in Table 4. For comparative purposes, the findings from studies that involved the use of a patient decision aid (PDA) are summarized first and those that did not, second.

Five studies involved the use of a PDA to elicit, and/or examine, patients': preferences for care in the context of advanced dementia [38,40,41]; decision making uncertainty about care in the context of advanced dementia [39]; and breast cancer surgical treatment preference, and level of decisional conflict [31]. The following findings are worth noting. In two studies, patients with lower scores on the REALM expressed preferences for aggressive care more frequently than patients with higher scores on the REALM [40,41]. In one of these studies, the treatment preferences of some patients with both lower and higher scores on the REALM changed after exposure to a PDA (i.e., a verbal narrative and a two minute video). These changes were: (1) more pronounced among patients with lower scores on the REALM, and (2) in the direction of less aggressive, or comfort, care [41]. Patients' reasons for these changes were not reported by the authors of this study.

It also is important to note the following. First, the PDA(s) used in these studies were not developed to reflect the needs of patients with diverse levels of HL. Second, level of education was used in one study as an indicator of HL despite the fact that: (1) the relationship between HL and level education has been disputed in the literature, and (2) three studies included in this review reported a lack of correlation, or congruence, between level of education and level of HL

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[18,34,51]. Third, in four studies, the care or treatment preferences of patients were elicited using PDAs that reflected a medical condition that most, if not all, patients in the study population did not have at the time of the study [38,39,40,41]. The majority of patients in these studies, therefore, were making hypothetical treatment, or care, decisions. Fifth, it was not always stated whether or not a third party (e.g., family member or friend) was included when the PDA was being used; including, two studies that involved a small number of patients that had been diagnosed with dementia. The significance of third party involvement is thus unknown. Sixth, the research designs used in these studies did not: (1) allow researchers to elucidate the mechanism(s) responsible for the observed findings, and/or (2) involve blinding researchers to the intervention and control group. The findings associated with these studies should be interpreted with these limitations in mind.

In the five studies that did not involve the use of a PDA, patients' scores on a measure of HL were examined in relation to: patients' uncertainty about decisions made about life sustaining treatment after exposure to a hypothetical scenario [29]; patients' assessments of their doctors' decision making [26,46]; patients' endorsement of a particular intervention (chemotherapy) for a fictitious group of patients [9]; and patients' decision to stop or decrease their medications (for asthma) [32]. Across these studies, the findings were variable, largely non-overlapping, and non-comparable.

*Insert Table 4*

#### **4.0 Discussion and Conclusion**

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#### *4.1 Discussion*

This review sought to answer the question: *What is known from the existing literature about the empirical relationship(s) between HL and the three stages of the TDM process?* The findings from this review confirm the continued relevance of recommendations that more “research is needed to map the extent to which health literacy affects risk communication and treatment decision making in actual clinical settings” [9<sup>(p165)</sup>] and explore “relationships between health literacy, information exchange, shared decision making and how health literacy can be described across cultures and social groups”[10<sup>(p50)</sup>]. There is also a need to examine the strength and stability of relationships across the entire TDM process given that the majority of studies included in this review examined empirical relationships relevant only to the first (information exchange) stage of the TDM process.

The existing evidence is weakened by several factors; including, the: (1) predominance of cross-sectional, correlational studies; (2) multiple issues identified in regards to the measurement of HL; and (3) significant lack of overlap in terms of the empirical relationships that have been examined. Cross-sectional, correlational studies do not allow for causal inferences to be made or the directionality of the relationship(s) to be determined. While HL may influence the process of TDM, the process of TDM may also influence HL, and this has important implication for judgements about whether, and how, it might be appropriate to “tailor” PDAs or SDM more generally to people who “start” with different levels of HL. Future research in this topic area may benefit from the use of more responsive measures of HL and research designs that allow for the testing of causal relationships and the elucidation of the directionality of relationships. The

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use of longitudinal, mixed-methods research designs may also allow researchers to explain quantitative findings, understand the implications of context, and examine relationships, and/or outcomes, at different levels and over time.

The multiple issues that were identified in regards to the measurement of HL have been reported elsewhere [56,57] but have yet to be addressed in research examining HL and TDM. Future research may benefit from the consideration, or incorporation, of Pleasant and colleagues [56] recommendations that the measurement of HL should: (1) be “explicitly built on a testable theory or conceptual framework of health literacy”; (2) explore core literacy skills (i.e., reading, writing, numeracy, speaking, and listening); (3) “measure on a continual, not a categorical basis”; (4) treat health literacy as a ‘latent construct’; (5) honour the principle of compatibility (i.e., use measures appropriate for the setting); and (6) “allow comparisons to be commensurate across contexts” [56<sup>(p15-17)</sup>].

Pleasant and colleagues also recommend that measures be developed to test the HL skills of the information giver (e.g., the health care provider, system, or disseminator of a public health message). To date, as this scoping review confirms, little attention has been paid to the HL skills of providers, and influence of their skills on the TDM process. This gap is surprising given that the treatment decision making process must involve, at minimum, two parties (i.e., the patient and the physician) [3]. Conceptual models of HL also suggest that health care providers can influence patients' HL [55].

The lack of overlap that exists across studies in terms of the empirical relationships that have been examined is problematic because it prevents comparisons of the findings across studies, and

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reduces the generalizability of the findings. The lack of overlap also has important implications for the cumulation of knowledge in this topic area; particularly, for the aggregation of findings of studies of effectiveness. To increase the generalizability of the findings, there is a need to improve theorization and/or replicate studies in different settings, using different health care providers, and different patient populations - including patients that have been relatively neglected (i.e., those diagnosed with non-cancer-related diseases as well as patients who are younger than 50 years of age, less health literate, male, non-White, non-English- and non-Spanish-speaking, and residing outside of the U.S.).

Strengths of this review include: the adoption of the Arksey and O'Malley [11] framework to guide the review; the adoption of the Charles et al. [3] TDM framework to allow for a broad and inclusive approach to the topic of interest; the consultation with the Evidence-Based Practice Centre librarian and team at McMaster University to select the most appropriate databases and search terms for addressing the research question; the team approach taken to the development and testing of the relevance screening criteria used in this study; and the use of two reviewers to screen all records for inclusion in this review.

The exclusion of non-English records is a limitation of this review. Future research should seek to identify relevant studies that are published in languages other than English. The charting of the data from studies by the first author only is another limitation. To reduce the likelihood of error, the data entered into Tables 2 through 4 were checked multiple times by the first author to ensure their accuracy. Tables 2 through 4 were also reviewed by all of the authors of this review and modified, as necessary, to ensure clarity and completeness. Finally, the exclusion of studies

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that examined numeracy, but did not explicitly mention the term HL, or use one or use measures of HL, is a limitation. A separate review that focuses exclusively on numeracy is currently in progress.

#### 4.2 Conclusion

The importance of HL to the three stages of TDM is not clear because of the knowledge gaps and multiple measurement-related problems that were identified in this review. Research is needed to address these gaps and problems in order to: (1) better understand the nature of (i.e., strength, direction, stability), and outcomes associated with, empirical relationships between HL and the three stages of TDM (both within and across patient populations and over time), and (2) inform policy initiatives that seek to accommodate, in clinical practice, the needs of patients with diverse levels of HL.

#### 4.3 Practice Implications

There are currently many uncertainties about how SDM, or the design and use of PDAs, should respond to patients with different levels of HL.

#### **Conflicts of Interest**

The authors do not have any actual or potential conflicts of interest to disclose.

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## **Appendix A: Search strategy used in MEDLINE**

1. HL.mp. (1680)
2. exp HL/ (629)
3. reading ability.tw. (942)
4. numeracy.tw. (333)
- 5. or/1-4 (2854) [synonyms or proxies for HL]**
6. exp Decision Making/ (101749)
7. (decision-making or decisionmaking).tw. (48780)
8. Treatment options.tw. (24617)
9. Treatment choice.tw. (1380)
10. Treatment alternatives.tw. (1405)
11. exp treatment refusal/ (9890)

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12. exp therapeutics/ (2991856)
13. exp decision support techniques/ (50121)
14. exp informed consent/ (32488)
15. exp patient participation/ (15439)
16. patient involvement.tw. (771)
17. patient acceptance of health care/
18. patient autonomy.tw.
19. patient-physician communication.tw. (321)
20. physician-patient communication.tw. (478)
21. physician-patient relations/ (54459)
22. information dissemination/ (7718)
23. exp Paternalism/ (2342)
24. or/6-23 (3235847) [*words and phrases related to TDM*]
25. 5 and 24 (919)
26. limit 25 to English language and 2013 (888)

### **Appendix C: Search strategy used in Embase**

1. health literacy.mp. (2198)
1. exp health literacy/ (638)
2. reading ability.tw. (1050)
3. numeracy.tw. (416)
4. or/1-4 (3537) [*synonyms or proxies for HL*]
5. exp patient decision making/ (3199)

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6. medical decision making/ (59330)
7. exp treatment refusal/ (9639)
8. treatment options.tw. (35113)
9. treatment choice.tw (1981)
10. treatment alternatives.tw. (1891)
11. decision aid\*.tw. (1278)
12. PDA.tw. (6082)
13. decision support tools.tw. (433)
14. exp informed consent/ (50472)
15. patient participation/ (13479)
16. exp patient autonomy/ (1758)
17. exp paternalism/ (2102)
18. exp doctor patient relation/ (72669)
19. exp information dissemination/ (10340)
20. exp patient attitude/ (200706)
21. patient-physician communication.tw. (403)
22. physician-patient communication.tw. (581)
23. or/6-23 (405320)
24. 5 and 24 (711) [***words and phrases related to TDM***]
25. limit 25 to English language (693)

## **Appendix C: Search strategy used in CINAHL**

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1. HL (search as a key word) (1255)
2. reading ability (search as a keyword) (245)
3. numeracy (search as a keyword) (210)
4. 1 OR 2 OR 3 (1658) [*synonyms or proxies for HL*]
5. Decision making, patient (explode) (8897)
6. Shared decision making (search as keyword) (736)
7. Informed decision making (search as keyword) (319)
8. Paternalistic decision making (search as keyword) (3)
9. Treatment options (search as keyword) (6476)
10. Treatment choice (search as keyword) (304)
11. Treatment alternatives (search as keyword) (235)
12. Therapeutics (explode) (619184)
13. Patient involvement (search as keyword) (449)
14. Refusal to participate (38)
15. Patient participation (search as keyword) (519)
16. Treatment refusal (2919)
17. Decision support techniques (explode) (957)
18. Consent (explode) (9948)
19. Patient autonomy (3640)
20. Physician-patient relations (13955)
21. Patient-physician communication (search as keyword) (116)
22. Physician-patient communication (search as keyword) (145)
23. 5-22 combined with OR (647976) [*words and phrases related to TDM*]
24. 4 and 23 (384) (Limit to English)

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#### **Appendix D: Search strategy used in Eric**

1. All (HL) (2353)
  1. All (Reading ability) (16110)
  2. All (Numeracy) (2433)
  3. 1 OR 2 OR 3 (20631) [*synonyms or proxies for HL*]
  4. All (patient decision making) (460)
  5. All (Shared decision making) (1815)
  6. All (Shared decision-making) (1751)
  7. All (informed decision making) (1102)
  8. All (making informed decisions) (1104)
  9. All (Informed consent and decision making) (53)
  10. All (patient decision aids) (49)
  11. All (decision support tool) (755)
  12. All (Paternalism) (164)
  13. All (treatment options) (692)
  14. All (treatment alternatives) (1760)
  15. All (treatment choice) (1236)
  16. All (refusal of treatment) (115)
  17. All (patient involvement) (363)
  18. All (patient participation) (407)
  19. All (autonomy of patients) (92)
  20. All (Physician-patient relationship) (1042)
  21. All (physician-patient communication) (334)
  22. All (patient-physician communication) (77)
  23. 5-23 combined with OR ( 9323 ) [*words and phrases related to TDM*]
- 4 and 24 (137) \* approximate count without duplicates

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