



Readability, Understandability and Action ability of Written Information Available for Patients Diagnosed with Prostate Cancer

Timothy A Skyring^{1,2}, Kylie J Mansfield^{1*}, Judy R Mullan^{1,3}

¹Department of Medicine, University of Wollongong, Wollongong, Australia

²Department of Urology, University of Wollongong, Wollongong, Australia

³CHRISP, University of Wollongong, Wollongong, Australia

ABSTRACT

Context: Following a diagnosis of prostate cancer men need to be able to read, understand and take action based on information accessed if they are to take part in the decision making process about their treatment options. However much of this information is written at a level beyond the health literacy of this group of men.

Objectives and design: By means of cross sectional survey this study investigated the health literacy of men diagnosed with prostate cancer and the information sources they accessed. The readability, understand ability and actionability of prostate cancer information sources were also assessed.

Results: Responses were received from 151 men (44% response rate), with a median age of 67 years, 21% with inadequate health literacy and most of whom had chosen surgery as their active treatment (56%). The majority of the respondents (80%) accessed four or more different information sources. The majority of information sources available were written above the recommended readability level (grade 8 or below), and had low 'actionability' scores (30%-50%) which were well below the recommended 70%.

Conclusion: Men newly diagnosed with prostate cancer often access information sources which are difficult to read, understand and take action upon. Clinicians, health authorities and non-government organisations must be made aware of the variable, but overall low, health literacy of men and work with consumer groups to develop good quality information that is readable, understandable and actionable thereby allowing men to have a better understanding of their treatment options and to be more involved in the decision making process.

Keywords: Prostate cancer; Health literacy; Patient information; Readability and understandability; Action ability

INTRODUCTION

Prostate cancer has a high incidence and remains the most common solid organ cancer diagnosed in Australian men, with an incidence rate of 129 cases per 100,000 persons [1]. This is similar to the incidence rate of 104 cases per 100,000 persons among American men [2]. Based on these estimates, approximately 17,000 Australian men and 192,000 American men will have been diagnosed with prostate cancer in 2020 [1,2].

The majority of prostate cancers (approximately 90%) are diagnosed at an early stage, while the cancer is still localised within the prostate, and therefore discussion about curative

treatment options between the physician and the patient is required [2]. Treatment options for early stage prostate cancer involves either immediate active treatment, surgery or radiation therapy, or conservative options including a watch and wait approach [2]. Both surgery and radiation therapy can be associated with significant side effects involving bladder, bowel and sexual dysfunction [3,4]. This, and evidence that active treatment may not prolong survival, make the decision about whether to undergo active treatment, and if so which treatment to choose, a difficult one [5,6].

To assist with this complex and difficult decision, a collaborative approach between the physician and patient encompass-

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Corresponding author Kylie Mansfield, Department of Medicine, University of Wollongong, Wollongong, Australia, Phone: +61 2 4221 5851; E-mail: kylie@uow.edu.au

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ing the principles of shared decision making is highly recommended [7]. In addition to verbal communication, this often involves the provision of written information. Given the extent of inadequate health literacy in the general population, any written information provided to patients should be clearly written, easy to read and understand [8,9]. It is recommended that written information be made available at or below an 8th grade level [10,11] or even perhaps a 5th or 6th grade reading grade [12,13]. However, despite these recommendations, available written information about prostate cancer and treatment frequently requires a higher level of health literacy than many men possess [14,15].

The aim of our study was to gain a better understanding of the health literacy of men newly diagnosed with prostate cancer, the prostate cancer information sources they accessed, and how helpful they found these sources, as well as the readability, understand ability and action ability of these prostate cancer information sources.

METHODS

The study was undertaken in two parts. Part A included an 18 item cross sectional survey. Part B investigated the readability, understandability and action ability of publicly available written prostate cancer information sources (including those available on the internet), compared to the written prostate cancer information resources provided by the urologist at the time of diagnosis.

Part A: Cross Sectional Survey

A total of 340 men newly diagnosed with prostate cancer attending a Urology clinic, between January 2015 and January 2017, were invited to complete and return by mail an 18 item questionnaire which included demographic questions, health literacy questions and questions about how informative and helpful they found the written prostate cancer information provided to them by the Urologist. This part of the study was approved by the Human Research Ethics Committee at our University (Protocol number 2016/955).

The health literacy questions included in the 18 item cross sectional survey comprised of the validated three item Brief Health Literacy Questionnaire: Question 1: "How often do you have someone help you read hospital materials?"; Question 2: "How often do you have problems learning about your medical condition because of difficulty understanding written information?"; and Question 3: "How confident are you filling out forms by yourself?" [16-18]. Response options for Questions 1 and 2 included: Always (1), Often (2), Sometimes (3), Occasionally (4) and Never (5). While response options for Question 3 were: Not at all (1), A little bit (2), Somewhat (3), Quite a bit (4) and Extremely (5). The overall Brief Health Literacy Score (BHLS) is the sum of the scores for these three items. A higher score indicates better health literacy with a maximum score of 15 and a combined score of 9 or less indicating inadequate health literacy [17-21].

The cross sectional survey also included five questions, adapted from the 'Silent Voice Survey', which asked questions about information sources which were accessed following their prostate cancer diagnosis and how informative/helpful they found these information sources [22].

Part B: Assessment of Readability, Understandability and Action ability of Prostate Cancer Information

Part B of the study involved a comparison of the readability; understand ability and action ability of information sources relating to prostate cancer and treatment options. The health information sources analysed in this part of the study included three patient information sources provided to patients attending the Urology service (Part A). These patient information sources prepared 'in-house' by the urology clinic physicians, included information about 'Open Radical Prostatectomy', 'Robotic Radical Prostatectomy' and 'Pelvic floor exercises for men'. The health literacy demand for these 'in-house' information sources, were compared with the health literacy demand of the Cancer Council of Australia booklet titled 'Understanding Prostate Cancer' [23], as well as the top 50 websites identified by the researchers using 'prostate cancer', 'prostate cancer treatment' and 'prostate cancer treatment side effects' as key word searches in Google (Figure 1). These key word search terms were used to identify if there was a difference in the health literacy demand between information found from a generic/basic google 'prostate cancer' search, and that for more complex/higher order concepts such as 'prostate cancer treatment' and 'prostate cancer treatment side effects'. In addition five websites were chosen by the research team as example websites (Figure 1). These example websites were identified using each the Google search terms listed above. These websites are: Prostate Cancer Foundation of Australia, (<https://www.prostate.org.au>) Cancer Council of Australia, (<https://www.cancer.org.au/cancer-information/types-of-cancer/prostate-cancer>); Mayo Clinic (<http://www.mayoclinic.org/diseases-conditions/prostate-cancer/basics/definition/con-20029597>); Movember foundation (<https://au.movember.com/mens-health/prostate-cancer>) and Wikipedia (https://en.wikipedia.org/wiki/Prostate_cancer)

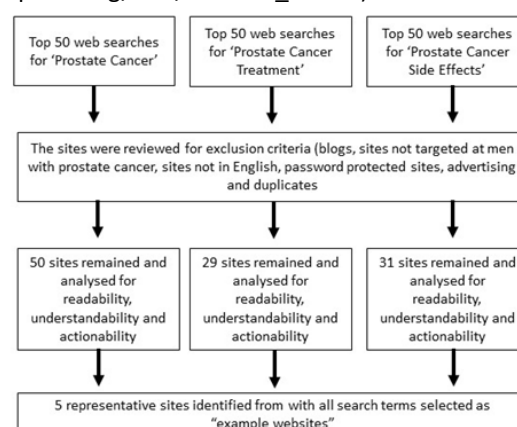


Figure 1: Results of independent word searches using the Google search engine

Readability: The readability of each of these sources of information was assessed by pasting a sample of the text (at least 300 words) from the handouts, booklets and/or websites into a proprietary online readability calculator 'Readability Formulas' (<https://www.readabilityformulas.com>); [24]. This calculator provides a 'consensus' grade level required to read the written information by averaging the results of seven validated reading

formulas: the Flesch Reading Ease formula, the Flesch Kincaid Grade Level, the Gunning FOG formula, the SMOG Index, the Coleman-Liau Index, the Automated Readability Index and the Linsear Write Formula.

Understand ability and action ability: The understand ability and action ability of the different information sources were assessed by using the validated and reliable 'Patient Education Materials Assessment Tool for Print Materials' (PEMAT-P), which has been used in a variety of health care, settings [25,26]. This tool gauges the likelihood that the information sources can be understood by people from diverse backgrounds, with varying levels of health literacy, by assessing 19 domains which include: purpose, use of everyday language, use of active voice, set out and logic of information, as well as use of visual cues. The tool also measures action ability, or how easily a person can identify what they need to do base on the information presented, by assessing seven of the 19 domains which include: use of clear steps to next action or response, clearly addressing the user and providing tools, such as checklists to help the user take action. The PEMAT-P scores materials on a scale of 0-100, with higher scores indicating greater understand ability and action ability, respectively [27]. The authors of the tool suggest that a score of greater than 70% is indicative of material that is understandable and actionable, respectively.

Statistical analysis: In Part A, the Mann Whitney test was used to test for significant differences between the BHLS, the number of information sources used and how informative the respondents found the information sources. An unpaired t test was used to determine if there was any correlation between having a partner, employment status, and the results of the BHLS. The Wilcoxon signed rank test was used to test for significance of relationship between age and internet use. Linear regression analysis was used to test for correlations between age, age of leaving school, the helpfulness of the information sources, and the BHLS.

In Part B, the Kruskal-Wallis test was used to test for significance between the 'consensus' grade levels of the different information sources, including those accessed from the internet and also to test for significance of difference between understand ability and action ability of the different information sources. All statistical analysis was performed using Prism 7 for MacOSX (GraphPad Software Inc.).

RESULTS

Part A: Cross Sectional Survey

Of the 340 eligible participants, 151 (44%) responded to the survey (n=151, response rate 44%) (Table 1). The median age of the respondents was 67 years (range 47 to 84 years) and just over half of the respondents had chosen surgery (radical prostatectomy) as their active treatment (56%, 84/151).

Health literacy of men newly diagnosed with prostate cancer: The median BHLS was 11, which is consistent with reports in diverse health care settings reporting BHLS medians ranging from 12 to 13.9 [18,19]. In our study, 21% of men had a BHLS of ≤ 9 indicative of inadequate health literacy (Table 1). There was a significant positive correlation between the BHLS and age leaving school (r^2 0.14, $P < 0.0001$) suggesting that staying at school longer is associated with higher health literacy. There was a negative correlation between age and BHLS although this

did not reach significance (r^2 0.015, $P=0.13$). There was no difference in the BHLS for men who had a partner, compared to those who did not ($P=0.35$) and similarly, there was no difference in the BHLS for those who were employed compared to those who had retired ($P=0.27$).

Table 1: Characteristics and health literacy of the study participants

| | Responses |
|---|---------------|
| Men having a partner % (n) | 87% (130/151) |
| Currently employed % (n) | 32% (48/151) |
| Describing themselves as retired % (n) | 55% (83/151) |
| Not born in Australia % (n) | 27% (40/151) |
| Education | |
| Age leaving school (years (range)) | 16 (12-22) |
| Finished high school % (n) | 75% (113/151) |
| University degree % (n) | 25% (38/151) |
| Health Literacy | |
| Median Brief Health Literacy Score, (IQR) | 11 (3) |
| Inadequate Health Literacy (BHLS ≤ 9) | 21.30% |

Information sources accessed: Almost all (91%) of the respondents reported being given information by their urologist upon diagnosis of their prostate cancer. The majority of respondents (61%-68%) rated the information they were given by their urologist as 'very informative', with a much smaller proportion of them (20%-22%) rating it as 'somewhat or very uninformative'. There was no difference in the BHLS among those who found the information informative versus those who found it uninformative.

In addition to the information provided by the Urologist, the majority of respondents (80%) accessed information from four or more different sources, with as many as 45% of them accessing six or more different sources. There was no difference in the number of information sources used by men with adequate health literacy (who used a median of six sources) to those with inadequate health literacy (who used a median of five sources) ($P=0.252$). There was however a significant negative correlation between increasing age and the number of information sources accessed ($r^2=0.02908$, $p=0.0369$), indicating that older men accessed fewer information sources.

Helpfulness of verbal information sources accessed: The majority of men (87%) found talking with their urologist about their prostate cancer and treatment to be very helpful (Table 2). However, there was a positive correlation between respondents with higher BHLS (health literacy) and how helpful they found the urologist as a source of information ($r^2=0.0288$, $P=0.0406$), suggesting that those with higher health literacy found the urologist more helpful.

A large proportion of respondents also reported using their general practitioner (72%), family, friends and other men with prostate cancer (60%) as information sources, with many of them (60%-70%) finding them to be 'very helpful'. For the 53% of respondents who reported using their radiation oncologist as an information source, almost all (92.5%) found the radiation oncologist to be 'very helpful'. There was no correlation between BHLS and helpfulness of any other individuals used as

information sources.

Helpfulness of 'written information sheets' provided by the treating urologist: A high proportion (77%) of respondents used the 'written information sheets' provided by the urologists (Table 2). However, only 71% of them found these to be 'very helpful' or 'vital' to their decision making process. There was no correlation between BHLS and the helpfulness of the 'written information sheets'.

Helpfulness of internet sources of prostate cancer information

Table 2: Heat map of helpfulness of information sources used by men following a diagnosis of prostate cancer

| | Urologist | GP | Family and friends | Other men | Radiation oncologist | Practice nurse | Pharmacist | Written Information sheets | Internet |
|--|-----------|------------|--------------------|-----------|----------------------|----------------|------------|----------------------------|----------|
| Number of respondents that used this source of information (%) | 146 (100) | 109 -72 | 92 (61) | 90 (60) | 80 (53) | 52 (34) | 18 (12) | 115 -77 | 73 (48) |
| Vital to my decision | 62 | 19 | 13 | 14 | 31 | 6 | 1 | 10 | 8 |
| Very helpful | 65 | 55 | 47 | 48 | 43 | 29 | 6 | 72 | 39 |
| Somewhat helpful | 14 | 29 | 28 | 25 | 4 | 12 | 8 | 30 | 26 |
| Not helpful at all | 5 | 6 | 4 | 3 | 2 | 5 | 3 | 3 | 0 |

Part B: Assessment of Readability, Understand Ability and Action Ability of Prostate Cancer and Treatment Information.

Readability: The consensus reading grade level for the three 'written information sheets' provided by the urologists were: grade 11 for the 'open radical prostatectomy' information sheet; grade 14.3 for the 'robotic radical prostatectomy' information sheet; and grade 12 for the 'pelvic floor exercises for men' information sheet (Figure 2). The booklet 'Understanding Prostate Cancer' prepared by the Cancer Council [23], had a lower average reading grade level of 10.4 (Figure 2). The average reading grade level of the top 50 websites identified using 'prostate cancer' as a search term on the 'Google' search engine was 8.0. This was significantly lower ($p<0.0001$) than websites identified using 'prostate cancer treatment' (average grade level 11.8) and 'prostate cancer treatment side effects' (average grade level 11.3) as search terms (Figure 2). The readability for the five example websites identified by the researchers is also shown in (Figure 2).

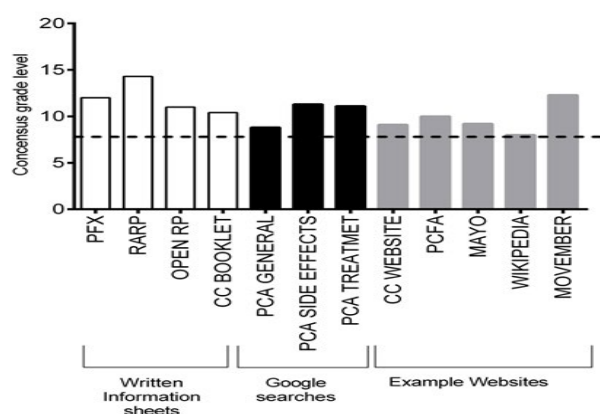


Figure 2: Readability as determined by the consensus grade level of written information sheets, google search results and selected websites. The dashed line represents the grade 8 readability level that is

accessed by men who responded to the survey.

Of the respondents (48%) who reported using the internet as a source of information, many of them (65%) found it to be 'very helpful or vital' to making their decision (Table 2). Respondents who accessed the internet for information were significantly younger than those who did not report using the internet ($p<0.0001$). However, there was no association between BHLS and how helpful men found the internet.

recommended in the literature for an information source to be useful to the general population (Buchbinder et al., 2001). Legend: Written information sheets: PFX=Pelvic floor exercises for men, RARP=robotic assisted radical prostatectomy, OPEN RP=open radical prostatectomy, CC BOOKLET=cancer council booklet, Google searches: PCA GENERAL=independent web search by authors for Prostate cancer in general, PCA SIDE EFFECTS=independent web search for Prostate Cancer side effects and PCA TREATMENT=independent web search for Prostate Cancer treatment. Example websites: CC WEBSITE=cancer council website, PCFA=Prostate Cancer Foundation of Australia, MAYO=Mayo Clinic, MOVEMBER=Movember Foundation.

Understand ability: The understand ability score for the 'written information sheets' varied between 71% for the 'Open Radical Prostatectomy' information sheet, 44% for the 'Robotic Radical Prostatectomy' information sheet and 82% for the 'Pelvic floor exercises for men' information sheet (Figure 3A). The understand ability scores for the Cancer Council of Australia booklet titled 'Understanding Prostate Cancer' scored the highest of all written materials analysed for this study at 88%. The average understand ability scores for the top 50 websites identified using the 'Google' search engine with the search terms 'prostate cancer', 'prostate cancer treatment' and 'prostate cancer treatment side effects' was 76%, 76% and 72%, respectively (Figure 3A). The understand ability scores for the example websites ranged from 44 to 83% (Figure 3A). Three of the five example websites had understood ability scores above 70%, these were the cancer council website, the website of the Prostate Cancer Foundation of Australia, and the Movember Foundation.

Action ability: The action ability scores for the 'written information sheets' were 40% for both the 'Open Radical Prostatectomy' and the 'Robotic Radical Prostatectomy', and 60% for the 'Pelvic floor exercises for men' (Figure 3B). The action ability score for the Cancer Council booklet was also low at 33% (Figure 3B). Similarly, the action ability scores for the top 50 websites identified by the researchers using the 'Google' search engine and the search terms 'prostate cancer', 'prostate cancer treatment' and 'prostate cancer side effects' were low at 13%, 30% and 25% respectively (Figure 3B). The action ability scores

for four of the five example websites ranged between 0 to 20% (Figure 3B) however the action ability score for the 'Movember Foundation' website stood out at 80%.

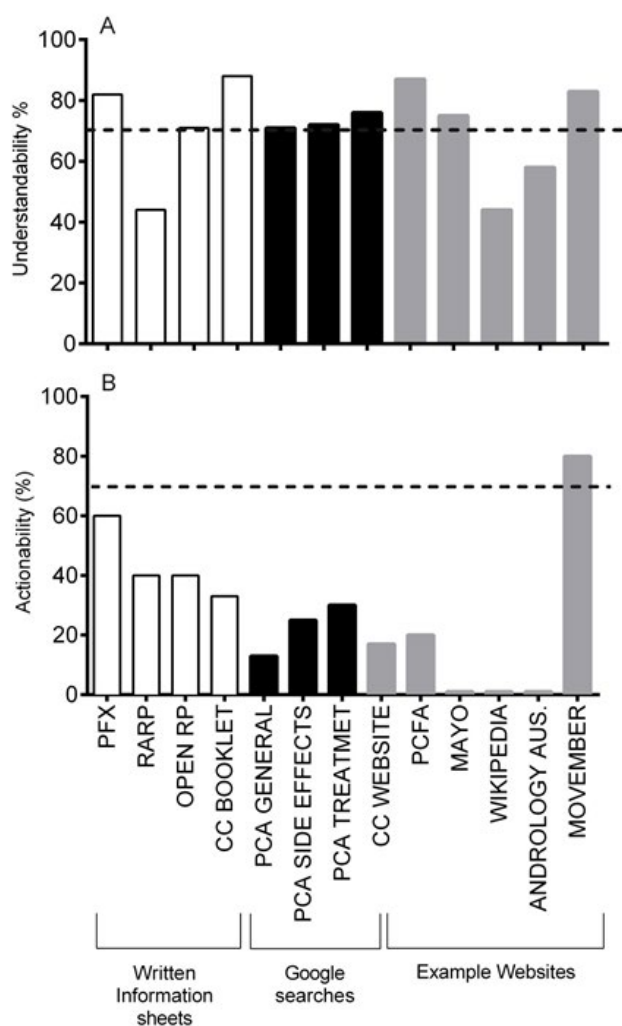


Figure 3: PEMAT-P measure of (A) understandability and (B) actionability of written information sheets, results of the google searches and example websites. The dashed line represents the 70% understandability and actionability level that is recommended in the literature for an information source to be useful to the general population. Legend: Written information sheets: PFX=Pelvic floor exercises for men, RARP=robotic assisted radical prostatectomy, OPEN RP=open radical prostatectomy, CC BOOKLET=cancer council booklet, Google web search: PCA GENERAL=independent web search by authors for Prostate cancer in general, PCA SIDE EFFECTS=independent web search for Prostate Cancer side effects and PCA TREATMENT=independent web search for Prostate Cancer treatment. Example websites: CC WEBSITE=cancer council website, PCFA Prostate Cancer Foundation of Australia, MAYO=Mayo Clinic, MOVEMBER=Movember Foundation.

DISCUSSION

Our study has identified that approximately 20% of men, newly diagnosed with prostate cancer, had inadequate health literacy which concurs with the very limited literature available for men with prostate cancer [28]. This proportion of men with inadequate health literacy is also similar to that reported for men within the same age group from the general population [8]. However, it is important to consider that in studies of this type, the study population who chose to respond to the survey

was self-selecting and it is likely that men with low levels of health literacy would choose not to participate. Therefore, it is likely that the percentage of men in the general population with inadequate health literacy is actually underestimated in this and other studies.

Our results also highlight that the readability of most information sources available to men with prostate cancer was above that recommended as suitable for the health literacy skill level of the general population [11]. Our study supported this by demonstrating that the information available to men diagnosed with prostate cancer, including the in house 'written information sheets', is at too high a grade level to be read and understood, especially by men with inadequate health literacy. In the current study, men with inadequate health literacy found information provided by the urologist less helpful than those with adequate health literacy. These results highlight that urologists need to be more aware of providing information, both verbal and written, which addresses the needs of all their patients, including those with inadequate health literacy. Furthermore, we found that the majority of information sources available for men with prostate cancer had actionability scores which were well below the recommended 70% [26]. This may mean that many men would find it difficult to be actively involved in the decision making process because of their inability to fully comprehend the information needed to communicate with their physicians.

Men receiving a diagnosis of prostate cancer tend to be older [2,29], as confirmed in our study (median age 67 years), and are less likely to seek health information with our results confirming that older men used fewer sources of information [30]. We also found that higher health literacy levels correlated positively with age at leaving school, which is supported in the literature [31,32]. This suggests that older and less educated men, diagnosed with prostate cancer, may require additional support when trying to engage in the decision making process about their prostate cancer treatment choices.

The majority of men in our study, and especially the younger men, were more likely to access multiple sources of information about prostate cancer and its treatment. These multiple sources included verbal information from their urologist, GPs, family and friends, as well as written information supplied by their urologist, the cancer council and the internet. These findings support the evidence from the literature which suggests that men, diagnosed with prostate cancer, will primarily access information provided by their treating physician, as well as information available from other health professionals, the lay literature (e.g., videos and pamphlets), friends with prostate cancer and the internet [33,34]. Treating physicians should therefore be aware that their patients, including those with inadequate health literacy, will be seeking information from multiple sources which may not always be reliable or evidence based. This may lead to confusion and an impairment of a patient's ability to take part in the decision making process. To help address this issue, physicians should suggest reliable and evidence based information sources to their patients.

The provision of information by the treating physician, and its understanding by the patient, are essential to enable patients to be involved in the decision making process [34-36]. It is important therefore, that information is presented in a way that is understandable for men of all levels of health literacy and

empowers them to act on the information [37]. The majority of men, both in our study and in the literature, reported using the material provided by the treating physician as the primary source of information. In our study, the average grade level required to read the 'written information sheets' provided by the urologists, the Australian Cancer Council booklet and the websites identified using 'prostate cancer treatment' and 'prostate cancer treatment side effects' was above grade 10, that is, they were all above the recommended 8th grade level [10,11,23]. These higher than recommended readability levels, are also evident in the Canadian Urological Association booklet on prostate cancer, which is written at an average grade level of 10.5 [15]. Similarly, Choi and associates found that prostate cancer patient education materials were written at a mean grade level of 9.6 [14]. In addition to the information provided by the urologist, patients have access to information about prostate cancer online. However, it has been estimated that 60% of the patient education materials available on the internet relating to a broad spectrum of patient health conditions (not specifically prostate cancer) required college or graduate level reading skills i.e., 13th grade or higher [38]. This perhaps indicates the inability of clinicians to appreciate the health literacy limitations of their patients [18,39].

Our study highlights that while the 'understandability' of written patient information was in general good (66%-88%, above the recommended 70%), the 'actionability' scores were low (30%-50%, well below the recommended 70%). While there have been no previous studies regarding the actionability of information relative to prostate cancer our findings concur with those found in studies for other health conditions [40,41]. This low level of actionability of the health related information available on the internet is important because it is not sufficient for men just to be informed about prostate cancer (able to read and understand available information) it is also important for them to be empowered to take action and make decisions about their treatment.

Strengths and Limitations

While the characteristics of our study population are representative of men presenting with prostate cancer generally this is a study from a single urological clinic in a regional town [2]. However, the health literacy of our study group is similar to that of the general population and the results and messages are therefore generalizable and may able to be extrapolated to any population especially those of older males.

CONCLUSION

This study highlights that approximately one quarter of the men, with a new diagnosis of prostate cancer, will have inadequate health literacy. This is of concern given that the majority of the patient information sources are written at too high a grade level and even though many of them were at the recommended level for understandability, almost all of them were well below the level recommended for actionability. This means that despite men accessing multiple information sources men may not have acquired and understood sufficient information to enable them to be fully involved in decision making about treatment options.

Practice Implications

After a diagnosis of prostate cancer men need to be provided with information that is clear and easy to follow. Clinicians treating patients with prostate cancer must enquire into men's health literacy to ensure they do not overestimate it, and also be aware that approximately half of all men at this age are not regular internet users. Not only must information provided be written so it is understandable for men, it must also enable them to take action and make a decision about treatment. Clinicians, health authorities and non-government organisations must be made aware of the variable, but overall low, health literacy of men and work with consumer groups to develop good quality information that is readable, understandable and actionable. It is interesting that this has been achieved by a charitable non-government organisation (Movember foundation: <https://au.movember.com/mens-health/prostate-cancer>) by providing brief but readable, understandable and most importantly actionable information, which gives a direct call to men to respond and take action towards a decision.

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CONFLICT OF INTEREST

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