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Deciding on PSA-screening – Quality of current consumer information on the Internet

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ABSTRACT

Purpose of the study: Given that screening for prostate cancer has the potential to reduce prostate cancer mortality at the expense of considerable overdiagnosis and overtreatment, the availability of core consumer information – correct, balanced and supportive of autonomous decision-making – is a must. We assessed the quality of consumer information available through the Internet per November 2009 and its possible contribution to informed decision-making by potential screenees.

Methods: Consumer information on PSA-screening was sought through the Internet in November 2009. Materials had to be targeted at potential consumers, offered by not-for-profit organisations, released in 2005 or after, in English or Dutch. Per material 2 of the authors assessed independently from each other whether standardised pre-defined topics were addressed, whether the content was correct and which approach was taken towards the decision-making process about uptake.

Results: Twenty-three materials were included, of which 11 were released (shortly) after the results of 2 large randomized-controlled trials (RCTs) that evaluated the effectiveness of screening for prostate cancer had been published in March 2009. That a PSA-test result can be abnormal because of non-cancerous conditions (false positive) and that it may miss prostate cancer (false negative) was not addressed in 2/23 and 8/23 materials, respectively. The risk of overdiagnosis and overtreatment was not mentioned in 6 out of 23. PSA-screening was presented as a usual thing to do in some materials, whereas other materials emphasised the voluntary nature of PSA-screening (‘it is your decision’). The content of 19/23 materials was considered sufficiently informative according to the pre-defined criteria, 12/23 materials were considered supportive of informed decision-making by men.

Conclusions: Most materials of not-for-profit organizations supplied adequate information about PSA-screening, whilst the degree of *persuasion* towards uptake reflected variations in opinions on men’s autonomy regarding their own health.

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1. Introduction

Although evidence for the potential effectiveness of PSA-screening in reducing prostate cancer mortality was only recently published[1] and population-based prostate cancer screening programs have not been introduced in Europe (yet), increasing numbers of PSA-screening tests have been performed in recent years. In the United States, up to 52% of the men at risk have had one or more PSA measurements,[2] and the numbers in Europe are rising.[3]

Screening for prostate cancer has the potential to reduce prostate cancer mortality at the population level.[1] At the individual level, however, screening participation involves an uncertain benefit and the risk of adverse side effects, e.g. unnecessary treatment of inconsequential disease.[4] It has become generally accepted that screen invitees should therefore be enabled to make their own individual evaluation of pros and cons and reach an informed decision about uptake. An informed choice or decision has two core characteristics: first, it is based on relevant, good quality information, and second, the resulting choice reflects the decision-maker's values.[5]

In PSA-screening the first step is 'just a blood test'.[6] A low PSA result provides reassurance, but a value above the threshold opens the door to a chain of events with risks of disadvantageous effects, such as overdiagnosis, overtreatment, false positive results and biopsy complications. In theory, decisions to continue or stop can be made at every step; in practice it is difficult to refuse additional diagnostic tests and treatment because 'both patients and physicians may experience strong positive reinforcement for screening. A patient will be grateful for a negative PSA result or a suspicious PSA result followed by negative biopsy results, whereas a positive PSA result followed by a cancer diagnosis makes a patient grateful that the cancer was detected early'.[7] Therefore, the first step, i.e. the decision whether or not to have PSA-screening, is decisive. Decision-making about taking this first step may be supported by information, made available by, e.g. ministries of health, cancer societies and hospitals. We will refer to this information as 'consumer information' – and not 'patient information' – because the men involved, who may consider uptake of PSA-screening, are not patients. Providing clear, accurate information about the risks of any proposed investigation or treatment, presented in a way potential screenees can understand,[8] is complex. The uncertainty of the subsequent steps is difficult to communicate[9] and disclosure of negative sides of screening may scare away specific groups, e.g. those with a low social economic status (SES), whilst these same groups may have an increased risk of prostate cancer.[10] Consider for instance the situation of African-Americans, who are at an increased risk to develop prostate cancer and more often than Caucasian-Americans have a low SES. Still, the whole screening process needs to be addressed to prevent a man from realising after being diagnosed that, in retrospect, ignorance about prostate cancer disease status was his preference after all.

Although not all potential screenees will want to make an individually based choice, according to Irwig and colleagues, still all screenees 'should be aware of the screening programme and have received and understood an agreed minimum of information about benefits and harms of the procedure'.[11] Such an agreed minimum of information, also referred to as 'core disclosure', can enable potential screenees to ask relevant questions and also help them to decide whether they want to enter the screening process or not.

We assessed the content of currently available consumer information and the approach taken towards the decision-making process of men who consider uptake of PSA-screening.

2. Materials and methods

2.1. *Consumer information*

In November 2009 consumer information was sought through the Internet by two of the authors (I.K., R.v.d.B.) using the following search terms: 'PSA patient information' (+.pdf), 'prostate screening information', 'PSA leaflet' (+pdf), 'PSA-screening leaflet PDF', 'prostate cancer screening leaflet PDF'. Per search the first 100–150 hits were checked for relevant materials that were targeted at potential consumers, i.e. men who consider uptake of PSA-screening, offered by not-for-profit organisations, released in 2005 or after, in English or Dutch. Materials with an unknown supplier, a content aimed at physicians and/or supplied by a for-profit organisation were excluded. Slightly adapted versions of already included materials were also excluded.

Each identified material was assessed by a pair of 2 of the 3 authors (I.K., R.v.d.B., M.L.E.B.), randomly selected per material. Initial scoring took place blinded to each other's scores. Subsequently scores were compared per case; any discrepancies in judgment were discussed until consensus was reached.

2.2. *Assessing the content of the consumer information*

In each material we assessed:

(1) the content;
(2) the approach towards the decision-making process about PSA-screening.

2.2.1. *The content*

We aimed to assess the quality of available consumer information on PSA-screening as objective as possible. We composed a list of topics based on recommendations for cancer screening information from Zapka,[12] a generic list of Wald[13] and a Guide for developing communication material for Breast Cancer Screening[14] (see Table 2). Per case we checked whether the pre-defined topics were addressed and if so, whether the information provided was correct. Not all topics on this list bear the same relevance. Various organisations, including the UK General Medical Council, have made lists of key points that are considered essential for potential screenees.[15–17] Based on these lists we chose the following key points to be discussed in materials: the purpose of PSA-screening; the procedure of a PSA-test; screen-detected versus clinically diagnosed prostate cancer; a priori possibility of false positive or false negative test results; the biopsy procedure; overdiagnosis; and the side effects of primary treatment of prostate cancer. Table 2 lists all topics that were assessed, including the key points, and illustrations of their wording in the materials. Considering the key point 'the purpose of screening' we differentiated by date of publication of the material: if released before March 2009 it should disclose that the effectiveness of PSA-screening in lowering prostate cancer mortality was not yet proven. If materials were released after the first results of two large RCTs of screening for prostate cancer were published, materials should report about that.

2.2.2. *The approach towards decision-making*

Evaluating how decision-making was approached in the materials and its potential effects on the decision process is more or less arbitrary. To objectify this procedure we used criteria based on those of the International Patient Decision Aid Standards (IPDAS) Collaboration.[18]

We assessed whether the materials allow potential screenees to

(1) know the options, i.e. participating in screening, not participating (or postponing the decision), and the features of PSA-screening, operationalised as the key points listed above;
(2) be clear about the features that matter most to them when deciding about PSA-screening;
(3) understand that individual preferences can affect the decision to have a PSA-test or not;
(4) discuss their preferences with others, e.g. their general practitioner;
(5) become involved in preferred ways: e.g. asking others, such as the physician, what to do or make a shared decision with the physician, and
(6) we assessed if the information could be expected to improve the match between the option that is chosen and the features that matter most to a man who considers PSA-testing, e.g. by a flow chart or diagram.

See Table 3 for an illustration of these criteria. An information leaflet was considered supportive for informed decision-making if at least 4 out of these 6 criteria were met.

2.3. *Informed choice*

We used the definition of an informed decision or choice as, defined by Marteau, one that is based on relevant knowledge whilst there is consistency between the decision-maker's values and his actual behaviour.[5] This implies that an informed choice to have PSA-screening occurs when a man has sufficient decision-relevant knowledge about the test, a positive attitude towards undergoing the test himself, and does undergo it. If a man has relevant knowledge about the test, has a negative attitude towards undergoing the test himself, and does not undergo it, he also makes an informed choice. All other combinations are considered uninformed. Having decision-relevant knowledge is thus essential for informed decision-making, although it is not a guarantee.

Table 1 – Overview of reviewed leaflets and websites on PSA-testing, identified at the world wide web in November 2009 by 2 of the authors (I.K., R.v.d.B.).

Source	ID NO	Country	Year	No. of words[a]
American Cancer Society[25]	A	USA	2009	III
National Cancer Institute[26]	B	USA	2009	III
Mayo Clinic[27]	C	USA	2009	II
Prostate Networking Group Cincinatti[28]	D	USA	2007	II
US dept of health & human services[29]	E	USA	2009	I
Br Colombia Cancer Agency, Canada[30]	F	Canada	2007	III
Min of Health and Long-Term Care, Canada[31]	G	Canada	2009	II
National Health Services[32]	H	UK	2009	II
CancerHelp UK[33]	I	UK	2009	II
NHS & Addenbrooke's hospital[34]	J	UK	2009	I
Dutch Cancer Society[35]	K	Netherlands	2009	III
Better Health Channel, Victoria[36]	L	Australia	2008	II
Association Int Cancer Research[37]	M	UK	2008	II
UpToDate Patient Preview[38]	N	?	2009	II
AUA Foundation[39]	O	US	April 2009	I
Saskalmchewan Ministry of Health[40]	P	Canada	2009	II
Prostate Cancer Charity[41]	Q	UK	2008	III
Healthline[42]	R	US	2007	II
Family Doctor[43]	S	US	2009	I
European Association of Urology[44]	T	Europe	2009	II
The Ohio State University Medical Center CCC – The James[45]	U	US	2008	I
American Ass Clinical chemistry[46]	V	US	2008	I
Urologists uk – Mr Rajiv Puri, Yorkshire Hospital Specialists Partnership[47]	W	UK	2006	II

[a] I: number of words <500; II: number of words >500 but <1000; III number of words >1000.

Table 2 – Content of the 23 information leaflets and websites; items, the number of time it was presented correctly and examples of citation from the leaflets and websites.

Item	Content correct ($n = 23$)	Citation
Purpose and benefits of screening for prostate cancer		
Early versus late moment of diagnosis[a]	21	It may give you an indication of cancer before symptoms develop (Leaflet H)
Early versus late moment of treatment	20	
Lower mortality	17,5	If treatment is successful, the worst possible outcomes of more advanced cancer, including death, are avoided (Leaflet H)
Proof about lower mortality[a]		
Published before March 2009	11	Does PSA testing really help? Based on medical knowledge today, we cannot answer this question definitively (Leaflet F)
Published after March 2009	4	Results from a large European study of prostate cancer screening found that men who had PSA testing had a 20 percent lower chance of dying from prostate cancer after nine years, compared to men who did not have prostate cancer screening (Leaflet N)
Feeling of relief	9	A normal PSA test, combined with a digital rectal exam, can help reassure you that it's unlikely you have prostate cancer (Leaflet C)
Screening on pc recommended (y/n)	4xyes, 2x±, 17xno	We recommend that men over 50 should have a PSA test every 5 years (Leaflet M)
Information on prostate cancer		
Seriousness/mortality	19	Even though many men with prostate cancer have non-aggressive tumours and do not die of the disease, a substantial number of men die from prostate cancer every year and many more suffer from the complications of advanced disease (Leaflet N)
Consequences for daily life/morbidity	12	
Treatment options for prostate cancer	16	
Treatment procedures	10	
Side effects of treatment[a]	16	You should know that side effects of radical treatment include a change in sexual experience and infertility (Leaflet H)
Follow-up after treatment	3	
Prevalence of prostate cancer at population level		
Incidence	12	According to the American Cancer Society, more than 215,000 American men are diagnosed with prostate cancer each year (Leaflet R)
Life-time risk – incidence (no mortality)	10	
PSA test		
What is PSA	22	Prostate specific antigen (PSA) is a protein produced by the prostate (Leaflet N)
How does a PSA test work[a]	22	The PSA test measures the amount of PSA in a sample of blood (Leaflet N)
Safety of the PSA-test	1	
Side effects of the PSA-test	1	
Pain because of PSA-test	0	
Time until result of PSA-test is available	0	
High-risk (positive) result		
Meaning	21	A positive PSA test is not a reason to panic; non-cancerous conditions are the most common causes for an abnormal test, particularly for PSA tests. On the other hand, a positive test should not be ignored (Leaflet H)
Rate of PSA-positive test results	4	
The consequence of a positive PSA-test	15	
A priori chance of false-positives test results[a]	20	75 percent of men with an abnormal PSA who had a prostate biopsy did not have prostate cancer (Leaflet N)

Table 2 ***(continued)***

Item	Content correct ($n = 23$)	Citation
Low-risk (negative) result		
Meaning	15	
Rate of PSA-negative test results	5	
The consequence of a negative PSA-test	12	
A priori chance of false-negatives test results[a]	15	It will also miss some men who do have cancer, giving them a false sense of security about their health (Leaflet G)
Side effects and disadvantages of screening		
Overdiagnosis (indolent tumours)[a]	17	You may end up with a diagnosis of prostate cancer that is not a threat to your health and doesn't require treatment (Leaflet C)
Overtreatment (radical treatment of indolent tumours)	17	
Distress due to screening procedure	12	It (PSA-test)may make you worry by finding slow-growing cancers that may never cause any symptoms or shorten your life (Leaflet H)
Unnecessary 'hospitalisation'	11	PSA Testing may lead to unnecessary anxiety and medical tests when no cancer is present (Leaflet F)
False feeling of relief	10	It can miss cancer and provide false reassurance (Leaflet H)
Detection rate		
No. of cancers per screened cohort	2	
Additional investigations		
Which (DRE, TRUS, biopsy)[a]	18	If either your DRE or PSA test is abnormal, the next step is a transrectal ultrasound (TRUS) and biopsy (Leaflet F)
Procedure of these investigations	14	A prostate biopsy involves having a rectal ultrasound and use of a needle to obtain tissue samples from the prostate gland (Leaflet N)
Side effects of these investigations	10	After the procedure, most men feel sore and you may see blood in the urine or semen (Leaflet N)
Time until result of these investigations	2	
Other important (medical) factors besides PSA in decision-making/ risk factors	20	All men who are African American, older than age 50, or have a positive family history of prostate cancer are at an increased risk of developing prostate cancer (Leaflet N)
Result of additional investigations		
Prostate cancer	19	
No prostate cancer	13	
False negative outcome	13	
Intent of the screening test voluntary:	21	
Extra information options e.g. phone no, website	18	
Overview and extras:		
Table with pros and cons of PSA test	10	
Flow diagram	2	
Name of sponsor c.q. financing body	20	
Date of publication	18	
Overall judgement		
Lay-out/format: appealing? (yes/no)	15x Yes, 1x±, 7x No	
Understandable (yes/no)	19x Yes, 4x No	

[a] Key point in consumer information for men who consider PSA-screening.

Table 3 – Criteria to evaluate the approach taken towards decision-making by men who consider PSA-screening, number of times the criteria were met and illustrations of wording.

Criterium	Criterium was met (*n* = 23)	Illustration
1. Helpful to know options, i.e. participating in screening, not participating (or postponing the decision), and the features of PSA-screening Y/N	19	See list of key points in Table 2
2. Helps potential screenees to understand that individual preferences can affect the decision to have a PSA-test or not Y/N	12	Your personal preferences will be an important factor in helping you to think about whether having a PSA test is right for you (Leaflet Q)
3. Helps potential screenees to be clear about option features that matter most when deciding about PSA-screening Y/N	16	We cańt tell you whether or not to have the test. Our role is to make you aware of the most up-to-date information. In deciding whether or not to have early detection tests, men must weigh the possibility of earlier diagnosis and treatment of potentially aggressive prostate cancer against the limitation of these tests (Leaflet G)
4. Helps potential screenees to discuss their preferences with e.g. their general practitioner Y/N	16	Your doctor is the best person to answer your questions and help decide what is best for you. Get your doctor's input before you decide if you should be tested (Leaflet F)
5. Helps potential screenees to become involved in preferred ways Y/N	10	The aim of this information sheet is to give you balanced information about the PSA test and things you may want to think about. We hope it will help you decide whether or not you should have the test, but there is no simple right or wrong answer. You may want to talk about this information with your doctor or a trained practice nurse and speak to your partner (Leaflet H)
6. Information improves match between chosen option and features that matter most to the informed potential user of the PSA-test, e.g. by a diagram or flow chart Y/N	11	Should I have the PSA-test? The benefits of PSA testing • It may reassure you if the test result is normal; • It may give you an indication of cancer before symptoms develop; • It may find cancer at an early stage when treatments could be of benefit; • If treatment is successful, the worst possible outcomes of more advanced cancer, including death, are avoided; • Even if the cancer is more advanced and treatment is less successful, it will usually extend life. The limitations of PSA testing • It can miss cancer and provide false reassurance; • It may lead to unnecessary worry and medical tests when there is no cancer; • It cannot tell the difference between slow-growing and fast-growing cancer; • It may make you worry by finding slow-growing cancers that may never cause symptoms or shorten your life; • 48 men will undergo treatment in order to save one life. (Leaflet H)

3. Results

Twenty-three materials were included, mainly offered by organisations from the USA (*n* = 11) and the United Kingdom (*n* = 7), but also from Canada, the Netherlands, and Australia, see Table 1. The information was released between 2005 and 2009 with number of words ranging from a minimum 450 to almost 6000 words. Eleven materials were released after March 2009.

3.1. *Content*

The proven lower mortality was addressed correctly in 4 out of 11 materials released after March 2009, see Table 2. Eleven out of 12 materials released before March 2009 correctly reported that lower mortality due to screening was not yet proven. The procedure of PSA-screening was addressed in all but one of the materials. The possibility that a PSA-test result can be abnormal because of non-cancerous conditions (false positive) and that PSA-test may miss prostate cancer (false negative) was not addressed in 2/23 and 8/23 materials, respectively. In five materials a description of the biopsy procedure was lacking. Overdiagnosis, i.e. a diagnosis of indolent tumours that would have remained harmless and undetected in the absence of a screening procedure, and overtreatment, i.e. treatment of indolent tumours were not addressed in 6 out of 23 materials. Side-effects of treatment were not described in 7/23 materials.

We considered the lay-out/format of 15 out of 23 materials as supportive for better understanding of the information, and the content understandable in 19 materials.

3.2. *Approach towards decision-making*

Two different approaches could be identified considering the communication about uptake of PSA-screening. Following the first approach, 'Paternalistic', men were told to be screened and PSA-screening was presented as a usual thing to do, e.g. 'We recommend that men over 50 should have a PSA test every 5 years (Folder M).

In the second approach, 'Informed choice', the voluntary nature of PSA-screening was emphasised and men were encouraged to make their own decision about uptake by talking to others or relying on personal preferences ('it is your decision'). Men were advised to actively make up their own mind, to ask their doctor's advice, to talk with their partner or important others, to weigh their own preferences, and then make a choice. For instance 'Give yourself time to make an informed decision. Talk to your spouse, partner or members of your family. Talk to the doctor. Bring this information with you. Consider the option that is best for you' (folder P).' Sometimes men were stimulated to do what was best for them referring to personal preferences. This was, e.g. phrased as 'Your personal preferences will be an important factor in helping you to think about whether having a PSA test is right for you (folder Q).'

In 19 out of 23 materials all key points as listed in Table 2 are presented (Table 3) and 16 materials helped men to be clear about those features that matter most to them in the decision process about uptake. Sixteen materials were helpful in encouraging a discussion with a general practitioner or family physician. Less materials were helpful for the realisation that preferences can affect uptake decision ($n = 12$), for becoming involved in preferred ways ($n = 10$) or in improving the match between the features that are considered most important for potential screenees and the chosen option ($n = 11$).

Out of 23 materials 12 were supportive for informed decision-making.

4. Discussion

Most materials of not-for-profit organizations supplied adequate information, whilst the variation in both content and lay-out was considerable. We found that the key points of PSA-screening, considered essential when deciding about uptake of screening, were discussed in 19 out of 23 materials. Whilst PSA-screening was not recommended in the majority of cases, the degree of persuasion towards uptake, i.e. the degree of guiding men towards the adoption of PSA-screening, reflected variations in opinions regarding men's autonomy over their own health. Twelve out of 23 materials were considered supportive of informed decision-making by men.

Twelve materials were released before the results of the prostate cancer screening trials became available. Although only one of the two screening trials showed disease-specific mortality reduction, resulting in some controversy about the effectiveness of PSA-screening, we adopt the view that PSA-screening can reduce prostate cancer mortality be it at the expense of substantial overdiagnosis and overtreatment. At the individual level overdiagnosis and overtreatment cannot be demonstrated. If that had been the case, they probably would not exist at the current level. A man who is deciding about having the PSA-test should be aware of the risk of overdiagnosis and overtreatment before he makes a decision, so that he can incorporate this knowledge in his personal trade-off of these risks and his chances of health benefit. For potential screenees and for physicians the moment to review the wisdom of a decision is before, and not after, the decision is made.[7] We recommend those who offer information about prostate cancer screening to keep the content up-to-date with new information that becomes available and incorporate trial results in their materials. In some situations one choice is clearly the best and healthcare professionals agree about that. This is not true for the question 'should I have a PSA-test or not'. That's why unbiased information should be provided to ensure autonomy[19] and allow informed decision-making. Given that screening has side effects and mortality reduction at the population level is modest, informed and shared decision-making remains the basis for recommendations about prostate cancer screening.[20] Good quality information remains relevant to allow individuals to balance the potential benefits and limitations of PSA-screening. We consider our list of key points as, what Irwig refers to as 'an agreed minimum',[11] a core disclosure, of such good quality information.

A sufficient level of decision-relevant knowledge is a prerequisite for informed decision-making. Achieving such a level of knowledge can be facilitated by written information. But although written information can be supportive for informed decision-making, no guarantee can be given that the decisions about uptake will be informed, even if materials were specifically designed to promote informed choice. Informed decision-making also requires an individual weighing of benefits and disadvantages of a screening test and having an attitude towards undergoing it oneself, which cannot be accomplished by leaflets. Whilst information provision is clearly necessary for the exercise of informed choice, evidence showed that leaflets of screening programs inform but not enable informed choice.[21] Understanding all benefits and disadvantages of PSA-screening requires a high level of health literacy. Not every man is capable and willing to make an informed decision all by himself. We think it as a good thing if men are encouraged to be involved in their own preferred way,[22] which could be discussing their thoughts about PSA-screening with experts, e.g. their general practitioner, or significant others. Patient autonomy should not turn into 'patient abandonment'.[23,24] Related to individual preferences and levels of health literacy, different men will want different information. Also, there are different ways to provide potential screenees with the information they need to make informed decisions, for instance using tailored information or web-based decision aids. Although technically feasible, the possibilities to tailor the content of information are currently not fully used and only a minority of providers of materials used internet features, such as adding links to more detailed information. We recommend a better use of the possibilities that Internet offers and assessments by screening programs whether decisions about uptake are informed, and – if needed – additional measures.

Strengths of the study are the inclusion of up-to-date materials, the rating of the materials according to predefined criteria from the literature,[12,13] and the independent rating of each material by a pair of two of the authors. A limitation of the study is the restriction to English and Dutch materials.

We conclude that most materials of not-for-profit organizations supplied adequate information about PSA-screening. The degree of persuasion towards uptake reflected variations in opinions regarding men's autonomy over their own health. The 'paternalistic' approach, i.e. telling men to have screening, has the ethical implications of maximising uptake, whilst ignoring the autonomy of individuals. The ethical implications of 'Informed choice' are maximising autonomy, whilst risking that not all potential screenees are able or willing to make an informed choice.

With the possible introduction of population-based screening and increasing numbers of men opting for PSA-tests, availability of core consumer information – correct, balanced and supportive of autonomous decision-making – is a must.

Conflict of interest statement

None declared.

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