

Cancer screening and accessibility bias: people want screening when informed it saves no lives

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Abstract: Some cancer screening programs are built on contentious evidence, but the public are generally positive about screening. Many professional organizations have settled on a fudge: allow the people to decide for themselves. Given the potential limitations of individual decision-making, there is increasing support for helping individuals to make better decisions. This paper presents experimental data supporting the claim that individuals are largely unresponsive to data about screening and base their decisions upon factors that professionals would consider inappropriate reasons for screening. The most plausible explanation for this phenomenon comes from accessibility bias. Professionals can no longer sustain the argument that, with respect to cancer screening, individual choice reflects a meaningful expression of autonomy.

Introduction

The medical response to cancer is multifaceted, incorporating research, treatment, aftercare and palliative care. Screening is a controversial part of the response, defined as testing asymptomatic people whose cancer risk is not known to be higher than the population baseline. Routine population cancer screening programs exist for colon cancer, cervical cancer, prostate cancer and breast cancer (Srivastava *et al.*, 2019). The evidence supporting these programs is variable. Colon cancer screening is an effective tool in reducing deaths (Hewitson *et al.*, 2007). On the other hand, the evidence supporting breast cancer screening is limited, and there is continuing debate regarding whether there is an absolute mortality reduction of somewhere between 1 in 100 and 1 in 2000 as found by the Marmot *et al.* report (2013), or whether breast

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cancer screening has no effect on absolute mortality (as reported by the Cochrane Review) (Gøtzsche & Jørgensen, 2013). Similarly, the best meta-analysis of screening for prostate cancer using prostate-specific antigen (PSA) blood tests found no reduction in absolute mortality (Ilic *et al.*, 2013). However, the US Preventive Services Task Force (USPSTF) advice that PSA screening should be avoided was opposed by many professional organizations (McGinley, 2017). Meanwhile, both breast cancer and prostate cancer screening tests lead to overdiagnosis, overtreatment and false positives, which result in significant psychological suffering and unnecessary tests such as biopsies, which have lasting physical effects (Bond *et al.*, 2013). For simplicity, the remainder of this paper will primarily address breast cancer.

Autonomy and screening decisions

Given the absence of medical consensus, professionals often ask the public to decide for themselves. To be sure, under normal circumstances patients give informed consent to any treatments or investigations, but ‘consent’ implies agreement to the medically recommended course of action. This is different from where there is no medically recommended course of action and the patient is asked to choose for themselves without medical advice: here, there is nothing to ‘consent’ to. The USPSTF advises that women aged 40–49 should make individualized choices based on personal preference: “Women who place a higher value on the potential benefit than the potential harms may choose to begin biennial screening” (US Preventive Services Task Force, 2019). The World Health Organization (2014) advocates supported decision-making and makes a conditional recommendation. Breast screening is recommended “if shared decision making strategies are implemented so that women’s decisions are consistent with their values and preferences.” British women report valuing “increased information about the benefits and risks of screening [making them] feel able to make their own informed decision” (Collins *et al.*, 2010).

Accordingly, European researchers have sought to improve information provision to promote individual decision-making (Henriksen *et al.*, 2015, Tran *et al.*, 2015). Gerd Gigerenzer noted that women across Europe overestimate the effectiveness of breast cancer screening, concluding that “only by correcting the current misinformation rate of 98% in various countries will women be in a position to make informed decisions” (Gigerenzer, 2014). He produced a simple information aid outlining the Cochrane Review findings in order to ensure women were adequately informed.

British focus group research suggested several potential limitations to this approach (Waller *et al.*, 2013). Firstly, the technical points of screening are

difficult to explain and understand, particularly the crucial statistical details regarding the magnitude of various risks. Secondly, many people do not want complicated information, but simply expect their health leaders to give clear directions: “if the NHS thinks people should go for screening, they should give unambiguous messages and not ‘frighten people off’.” Thirdly, there is evidence that presenting people with data does not change their beliefs about screening: “although [participants] felt the information was important, it generally had little impact on their beliefs about screening and their future intentions to participate.”

Statistical literacy may be teachable, and perhaps people can be persuaded to make their own decisions, but the last point has more significant implications. Enabling autonomy is laudable as far as it goes, but it is limited where failures of reasoning, lapses in attention or miscalculations prompt a choice that in fact works against people’s interests. This present paper suggests that the word ‘cancer’ may activate accessibility bias, thereby producing such errors by leading people to focus on the ‘accessible’ threat of cancer rather than to evaluate the relevant information.

According to the *reasons-responsive* conception of autonomy, sensitivity to relevant facts and insensitivity to irrelevant facts are necessary preconditions for meaningful autonomy (Fischer & Ravizza, 1993). Under normal conditions, the training and experience of the doctor is the single most relevant fact: trusting a doctor is a manifestation of autonomy. But in many cancer screening tests there is no medical recommendation, so autonomous decision-makers must seek and weigh other facts. If they do not respond to relevant available facts, then their autonomy is, on this understanding, limited.

Salience and accessibility bias

Decision-makers’ deliberative capacities can be bypassed by certain elements of choice architecture. ‘Salience’ and ‘accessibility bias’ do this by occupying the decision-maker’s attentional capacity (Levy, 2017). The UK’s Cabinet Office reported that “Salience explains why unusual or extreme experiences are more prominent” in decision-making (Dolan *et al.*, 2010). Given that “we tend to unconsciously filter out much information as a coping strategy,” people’s decisions are often disproportionately based on factors that are easy to understand and accessible (Dolan *et al.*, 2010). Accessibility bias arises because “information that can be more easily retrieved from memory tends to dominate judgments, opinions and decisions” (Iyengar, 1990). This can make it difficult for people to weigh information correctly.

Cancer is a salient and accessible idea. It is easily understood, and its extreme implications permeate popular culture (Goslinga, 2015). Lee and Loisselle

(2012) argue that most people's personal awareness of cancer involves a constant threat of cancer. The sense that cancer can strike anybody at any time is promoted by the suggestion that entirely asymptomatic people should attend screening tests and by the slogan "Cancer doesn't discriminate" (Weir-Hughes, 2005). Despite the persistent low-level threat, a cancer diagnosis, scare or bereavement is often a particularly striking, distinct and memorable experience. Moreover, the public conception of cancer may not account for the possibility of asymptomatic cancer that is not life-threatening. Because of its simplicity and significance, cancer is likely to activate accessibility bias, distorting people's ability to weigh information.

A possible solution

If the salience of the word 'cancer' overwhelms rational evaluation, then a possible solution would involve discussing screening tests without using the word 'cancer', only mentioning cancer after the patient has had a chance to appraise the data and allowing them to make their final decision then. It is hypothesized that elements of inertia or anchoring would lead people to stand by their initial rational evaluation. The next section describes an experiment evaluating whether the salience of cancer screening overwhelms our ability to evaluate cancer rationally, leading people to make inconsistent and arguably irrational decisions.

Methods

An experiment was designed to test the hypothesis that screening uptake would increase when cancer was mentioned. Secondary aims were to assess population willingness to take a harmful screening test and to assess whether Gigerenzer's informational nudge adequately dealt with concerns.

An online survey was created using Qualtrics. Participants were recruited using the mTurk platform, which pays members of the public to undertake surveys. Users of mTurk can take as many or as few surveys as they choose and tend to be regular survey takers rather than one-off users. Only participants from the USA were accepted and no other parameters were set. Thus, the survey was open to all Americans with Internet access. People who agreed to participate in the survey were aware that the survey was about health and understood that they could leave the survey at any time but would not be paid. The mTurk survey has been used successfully to recruit survey participants for other behavioral economics experiments (Sunstein, 2019). The experiment was piloted on students at Harvard University. We aimed to include 400 participants in the experiment. All included surveys

were completed between 19 and 20 September 2019. The survey randomized participants to one of two arms.

Arm 1: in Part (a), participants were presented with data on screening for ‘Disease A’ and asked whether they would accept that screening test. In Part (b), all participants were updated that ‘Disease A’ is in fact a form of cancer and asked whether they would now accept the screening test.

Arm 2: participants were presented with data on screening for ‘Cancer A’ and asked whether they would accept that screening test.

In both arms, a yes/no forced choice was used.

The data shown to both arms were loosely based on the data from Gigerenzer’s informational box, but were not exactly the same. The data used show that those who take the test do not live longer but are exposed to an unnecessary risk of scarring.

This is not a test of breast cancer acceptability; neither the words ‘breast cancer’ nor exact numbers matching breast cancer screening were used (Gigerenzer, 2014). Roughly similar statistics are accepted by opponents of breast cancer screening, but are contested among those who support breast cancer screening. Advocates of breast cancer screening argue that the best evidence suggests an improvement in mortality. (They do not argue that the data show overall harm but screening should be provided anyway.)

Presenting these data allowed the experiment to address its secondary objectives. The information given does not support the screening test, but instead portrays the screening test as having harms and no benefits. If people are responsive to information on screening, then we would expect people to decline this screening test. The wording shown to participants is given in [Table 1](#).

Demographic information was collected for sex, income, educational level, race and age (less than 40 versus 40 or over). Statistical analyses were performed in Stata-14. Analysts were not blinded to the randomization status of participants.

Results

A total of 411 people took the survey; 264 were under 40 years old (U40s), while 147 were aged 40 years or older (40+s). A total of 113 reported previous screening and 298 denied previous screening. There were slightly more women than men (233 versus 178). There was no significant difference in the distributions of these groups to either arm. Participants reported a wide range of educational and income levels, but these did not correlate with any results.

Willingness to undergo screening varied as different words were attached to the same data. The results are shown in [Table 2](#).

Table 1. The prompts given to participants in arms 1 and 2.

Arm 1, Question (i)	<p>A screening test for Disease A is available. 4 of every 1000 people who choose to take the test die of Disease A within 5 years. 5 of every 1000 people who choose not to take the test die of Disease A within 5 years.</p> <p>Adding together deaths from all causes, including Disease A, 2% of people who choose not to have the test will die within 5 years and 2% of people who choose to have the test will die within 5 years. An additional 1% of people who have the test will have a ‘false alarm’, requiring further testing, which could cause scarring. Would you take the Disease A screening test?</p>
Arm 1, Question (ii)	<p>Disease A is a form of cancer.</p> <p>A screening test for Disease A is available. 4 of every 1000 people who choose to take the test die of Disease A within 5 years. 5 of every 1000 people who choose not to take the test die of Disease A within 5 years.</p> <p>Adding together deaths from all causes, including Disease A, 2% of people who choose not to have the test will die within 5 years and 2% of people who choose to have the test will die within 5 years. An additional 1% of people who have the test will have a ‘false alarm’, requiring further testing, which could cause scarring. Would you take the Disease A screening test?</p> <p>You said [“No” or “Yes”]</p> <p>Would you take the Disease A screening test now you know that Disease A is a form of cancer?</p>
Arm 2	<p>A screening test for Cancer A is available. 4 of every 1000 people who choose to take the test die of Cancer A within 5 years. 5 of every 1000 people who choose not to take the test die of Cancer A within 5 years.</p> <p>Adding together deaths from all causes, including Cancer A, 2% of people who choose not to have the test will die within 5 years and 2% of people who choose to have the test will die within 5 years. An additional 1% of people who have the test will have a ‘false alarm’, requiring further testing, which could cause scarring. Would you take the Cancer A screening test?</p>

Result 1: the majority of people accepted harmful cancer screening

The wording of the survey specified that the screening test was harmful, but 56% of people still accepted screening for a cancer. Although slightly less than half accepted ‘disease’ screening with the same facts, this increased above 50% when they were updated that the disease was cancer.

Result 2: the U40s were overall more enthusiastic about screening

Overall, U40s were more open to screening than 40+s. Among people who were told the screening test was for a disease, U40s were twice as likely as 40+s to accept screening (60% versus 30%, $p < 0.0001$). After they were updated that the disease was a cancer, U40s remained significantly more likely than 40+s to accept screening (69% versus 49%, $p = 0.0053$). However, when the groups were initially told that the screening test was for

Table 2. The percentage of participants who would take the screening test in each arm, with 95% confidence intervals.

	Arm 1, question (i)	Arm 1, question (ii)	Arm 2
Total	49% (102/209) (42.2–55.8%)	61% (128/209) (54.4–67.6%)	56% (113/202) (49.2–62.8%)
U40s	60% (78/129) (51.5–68.4%)	69% (87/129) (61.0–77.0%)	56% (76/135) (47.6–64.4%)
40+s	30% (24/80) (20.0–40.0%)	49% (39/80) (38.0–60.0%)	55% (37/67) (43.1–66.9%)

The percentage of participants who accepted screening under each arm is broken down by age group.

U40s = under 40 years old; 40+s = aged 40 years or older.

cancer, there was no difference between the age groups regarding willingness to accept screening for cancer (56% versus 55%, $p = 1.0$).

Result 3: the 40+s were more likely to accept screening for ‘cancer’ than ‘disease’

Surprisingly, among U40s, there was no significant difference between willingness to be screened for cancer and willingness to be screened for a disease ($p = 0.1669$). In fact, screening uptake was slightly (not significantly) higher when cancer was not mentioned (56% versus 60%, $p = 0.5333$). Among 40+s, mentioning cancer led to a significantly higher screening uptake, and there was a much lower uptake of ‘disease’ screening among 40+s (30% versus 55%, $p = 0.0025$).

Result 4: the 40+s changed their mind when ‘disease’ was updated to ‘cancer’

The 40+s demonstrated a major increase in screening uptake when updated that the disease was a cancer. Among 40+s, updating significantly increased the screening uptake (30% versus 49%, $p = 0.0231$).

Result 5: withholding the word ‘cancer’ is not an effective strategy for reducing screening

Some people were immediately told that the screening test was for a cancer; other people received this information after making their initial judgment. The overall effect was not statistically significant. The result was not significant among 40+s. However, U40s were significantly more likely to accept (harmful)

Box 1. Summary of results.

Result 1: A majority of people accepted harmful cancer screening
 Result 2: The U40s were overall more enthusiastic about screening
 Result 3: The 40+s were more likely to accept screening for ‘cancer’ than ‘disease’
 Result 4: The 40+s changed their mind when ‘disease’ was updated to ‘cancer’
 Result 5: Withholding the word ‘cancer’ is not an effective strategy for reducing screening

U40s = under 40 years old; 40+s = aged 40 years or older.

screening when the word ‘cancer’ was withheld and added later than when cancer was mentioned at first blush.

These main results are summarized in [Box 1](#).

Discussion

This experiment revealed that many people, including the majority of U40s, would accept harmful screening tests whether told they were for cancer or just for ‘disease’. Harmful screening was more acceptable when cancer was mentioned, particularly among 40+s, who were also much more likely to change their mind when cancer was mentioned. However, the theory that withholding the word ‘cancer’ at first appraisal would promote more reticent overall decision-making was proven wrong.

There is little prior research comparing general attitudes toward cancer screening by age, possibly because the U40 population tends to be excluded from all screening programs except cervical cancer screening. This experiment revealed overall positive appraisal of screening among U40s, which made the other results more difficult to interpret. Specifically, the acceptance of harmful disease screening by U40s was as high as the acceptance of cancer screening by 40+s. Setting aside that complicating factor, there remained an overall effect and subgroup effects. This section will explore why so many people (of all ages) indicated that they would take a harmful screening test and how the word ‘cancer’ affected decision-making (particularly among the 40+ group).

Why were people open to harmful screening?

Many people stated a desire for screening tests even when shown that the tests had harms but no benefits.

Possibly, as Waller *et al.* (2013) found, they simply did not understand the data. This would be a concerning conclusion because it calls into question

individuals' ability to consent to any screening test whether the data show effectiveness or ineffectiveness. It would be irresponsible for professionals to transfer decision-making to people who cannot make an informed decision.

Another possibility is that participants thought they could gain a secondary benefit from screening. Their life may not be saved, but perhaps they hoped to gain a few months or have sufficient warning to set their affairs in order. Members of the public place low value on avoiding false positives, so these possibilities might have outweighed the risk of false alarms and scarring, allowing them to choose screening (Schwartz, 2000). This explanation is concerning because it is out of keeping with the claims of pro-screening professional organizations that screening aims to stop people dying from cancer. The rationale for screening according to the USPSTF is "survival may be improved for [certain] types of cancer when they are identified at localized stages" (Nelson *et al.*, 2016). Similarly, the Centers for Disease Control and Prevention (2018) state, "The benefit of screening is finding cancer early, when it's easier to treat." The American Cancer Society (*n.d.*) states that its "breast cancer screening guidelines are developed to save lives by finding breast cancer early."

This is not the first evidence that the public want screening under circumstances where professionals would consider it inappropriate. A recent survey of healthy men and women found that 49% would want screening for a cancer that could not be treated and 45% would want to be screened for a slow-growing cancer that would never cause any symptoms (Waller *et al.*, 2015). It seems likely that people are choosing screening for reasons that professionals would not consider good reasons for screening.

Direct-to-consumer campaigns have at times been criticized for exaggerating the potential benefits of screening (Woloshin & Schwartz, 2012). Long-term positive exposure to these messages could also explain why people accept screening tests. Similarly, many people in our sample had undergone previous screening tests, presumably with physician assent. Perhaps the advice from these sources had led people to consider screening tests favorably without distinguishing effective and ineffective tests. It is not irrational to believe that screening tests are probably a good thing because they tend to be advised by professionals. However, it problematizes professional deferral to individual autonomy if pro-screening attitudes prevent appraisal of relevant evidence.

It is not clear what causes people to accept screening when shown data revealing it is harmful and not beneficial. It may be an inability to evaluate the data, a belief that screening has other minor benefits or the overwhelmingly positive appraisal of screening. The truth may be some combination of those three factors, but that still creates problems for people who wish to defer to individual autonomy in medical decisions.

What caused the effect of the word 'cancer'?

Although harmful disease screening was accepted on the whole, acceptance increased significantly among 40+s when the word 'cancer' was used. As suggested above, this could be explained by the salience and accessibility of 'cancer'. The word 'disease' is vague and does not have the same baggage as cancer. People are aware that diseases carry a certain mortality risk. Although many diseases have a lower mortality than cancer, that should not bias people who are shown mortality data.

Some might argue that the effect of the word 'cancer' comes from personal impact: people are more likely to choose screening because of personal experience. This explanation does not hold because answers to the survey were not associated with whether participants had personal or family experience of a cancer diagnosis or personal experience of cancer screening.

'Cancer' and 'disease' have different literal meanings. Perhaps substituting one for the other changed the substance of the question, or perhaps participants imported external knowledge that cancer is often life-threatening. But participants were given identical data accompanying the questions, so preventing death was no reason to prefer screening for 'cancer' than 'disease'. Participants may have known that early diagnosis of cancer reduces mortality, but the questions explained that this screening test did not reduce overall mortality. People might want an early warning so that they can make plans if they have a terminal illness, but that is true whether they have cancer or any other potentially fatal disease. That is a possible reason to choose screening, but it ought not to lead people to prefer 'cancer' over 'disease' screening.

There is a gap between the neutral response unaffected by the baggage of the word 'cancer' and participants' actual responses, which can be filled by the explanation from salience and accessibility. When participants saw the word 'cancer', it influenced their reasoning to a greater extent than when they thought about life-threatening diseases in general. Beyond the salience of the word 'cancer', people also associate 'screening' with 'cancer' more than 'disease'. Although this contextual salience is not a rational reason to choose cancer screening, cancer screening is a well-known and memorable idea, allowing people to connect with cancer screening and, again, overvalue it within their reasoning. These biases best explain the gap between the perfectly rational response and participants' actual responses.

Implications of this experiment for potential solutions

The medical literature does not include a formal evaluation of the simple data that Gigerenzer presents as a means of promoting informed consent. The results of this experiment represent a significant limitation to his approach:

more often than not, people who see his data want to be screened (56% versus 44%). Showing people that screening has harms and no benefits does not stop them wanting to be screened. Worse still, this experiment undermines the notion that people are able to evaluate facts about screening. It is not just that a minority of people misinterpreted the data; the majority of participants agreed to screening when they were told it was harmful.

Contrary to Gigerenzer's approach, this experiment suggests that people make screening decisions based on irrelevant factors such as ordering and wording. Improving the quality or clarity of information is unlikely to overcome these effects because the idea of cancer interferes with rational appraisal of the data. As Gigerenzer notes, cancer's social meaning has been cultivated by charities and professionals. His informational nudge is a valiant but unsuccessful attempt at undoing this work. Driedger *et al.* (2017) have described the challenges involved in reversing the pro-screening public information campaign, calling it "un-ringing the bell."

This paper's attempt to nudge participants into more considered choices also failed. Withholding the word 'cancer' during the initial decision reduced screening uptake, but the first expression of opinion lacked stickiness. Rather, there was significant rebound when the word 'cancer' was reintroduced. Overall, there was no significant difference in the final judgments of those in Arm 1 and Arm 2. I had postulated that the initial statement could act as a commitment or anchor, and that inertia might lead people to stand by their initial statement. Instead, the second chance favored screening. Those who initially declined screening may have interpreted the word 'cancer' as a hint or prompt to reconsider, whereas perhaps those who initially accepted screening felt vindicated. Another explanation for this asymmetry is that the word 'cancer' prevented participants from recalling the basis of their initial decisions, although a direct comparison with a different word was not included in this experiment.

Strengths and limitations

This experiment uses a novel online survey methodology to sample the views of the public about screening. This is appropriate given that screening tests are offered to members of the public rather than to patients.

It is difficult to generalize from these results. Like other research into public attitudes to cancer screening, this experiment was conducted in an artificial setting, and the participants' reported preferences may not align with their actions *in vivo*. It is also possible that participants found the data difficult to understand; however, this limitation does not reduce external validity, given real-life data about screening are also difficult to understand.

Conclusions

These findings contribute evidence that the desire to participate in cancer screening does not reflect deeply held “values and preferences” (World Health Organization, 2014). Attempts to reorient decision-making around facts are problematized by evidence that the public are relatively insensitive to facts about whether screening works. Professional organizations should accept that people are not engaging in decision-making that professionals would consider sound, when they consent to screening. Many will consent even when presented with evidence that screening does not work.

It may be that breast or prostate screening tests are efficacious, in which case they should be encouraged for all on the basis of well-being, accepting that fully informed consent is unlikely. On the other hand, these screening tests may do no good (only harm), in which case the desire to be screened seems to be relatively insensitive to evidence. Whichever way we interpret the underlying evidence, asking people to make cancer screening decisions for themselves does not reveal meaningfully autonomous desires and cannot satisfactorily fill the evidential vacuum.

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