Review | LESS IS MORE

Patients' Expectations of the Benefits and Harms of Treatments, Screening, and Tests
A Systematic Review

Tammy C. Hoffmann, PhD; Chris Del Mar, MD, FRACGP

IMPORTANCE Unrealistic patient expectations of the benefits and harms of interventions can influence decision making and may be contributing to increasing intervention uptake and health care costs.

OBJECTIVE To systematically review all studies that have quantitatively assessed patients' expectations of the benefits and/or harms of any treatment, test, or screening test.

EVIDENCE REVIEW A comprehensive search strategy was used in 4 databases (MEDLINE, Embase, Cumulative Index to Nursing and Allied Health Literature, PsycINFO) up to June 2013, with no language or study type restriction. We also ran cited reference searches of included studies and contacted experts and study authors. Two researchers independently evaluated methodological quality and extracted participants' estimates of benefit and harms and authors' contemporaneous estimates.

FINDINGS Of the 15 343 records screened, 36 articles (from 35 studies) involving a total of 27 323 patients were eligible. Fourteen studies focused on a screen, 15 on treatment, 3 a test, and 3 on treatment and screening. More studies assessed only benefit expectations (22 [63%]) than benefit and harm expectations (10 [29%]) or only harm (3 [8%]). Fifty-four outcomes (across 32 studies) assessed benefit expectations: of the 34 outcomes with overestimation data available, the majority of participants overestimated benefit for 22 (65%) of them. For 17 benefit expectation outcomes, we could not calculate the proportion of participants who overestimated or underestimated, although for 15 (88%) of these, study authors concluded that participants overestimated benefits. Expectations of harm were assessed by 27 outcomes (across 13 studies): underestimation data were available for 15 outcomes and the majority of participants underestimated harm for 10 (67%) of these. A correct estimation by at least 50% of participants only occurred for 2 outcomes about benefit expectations and 2 outcomes about harm expectations.

CONCLUSIONS AND RELEVANCE The majority of participants overestimated intervention benefit and underestimated harm. Clinicians should discuss accurate and balanced information about intervention benefits and harms with patients, providing the opportunity to develop realistic expectations and make informed decisions.

Author Affiliations: Centre for Research in Evidence-Based Practice, Faculty of Health Sciences and Medicine, Bond University, Queensland, Australia (Hoffmann, Del Mar); School of Health and Rehabilitation Sciences, University of Queensland, Brisbane, Australia (Hoffmann).

Corresponding Author: Tammy C. Hoffmann, PhD, Centre for Research in Evidence-Based Practice, Faculty of Health Sciences and Medicine, Bond University, Gold Coast, Queensland, Australia 4229 (thoffmann @bond.edu.au).

The uptake of medical interventions (treatments, tests, and screening) is ever increasing and cost more than $2.5 trillion, or nearly 18% of the US gross national product, in 2010.[1] The overuse of many medical interventions is recognized[2] yet poorly documented and therefore almost certainly more prevalent than is realized.[3] It is compounded by overdiagnosis of many conditions.[4] This drives up the costs of health care unnecessarily, putting strain on, and increasing anxieties about, the sustainability of current models of care. It may also unnecessarily harm patients—"overtreatment" implying an unfavorable benefit-to-harm ratio because most screens, tests, and treatments have some harms, and these may outweigh the benefits.[4,5] Overdiagnosis can harm patients in a number of ways, including the potential for emotional distress caused by the disease label itself,[6,7] as well as the resultant unnecessary treatment, with associated risks and costs, of latent disease that might never otherwise have caused symptoms or early death.[4]

Why medical interventions are overused is unclear, but suggested factors include the preferences and expectations of health care users,[8] patient assumptions that more tests and treatments indicate superior care, payment systems that favor providing an intervention over talking with patients, defensive medicine, and the efficiency appeal of ordering a test or prescription over the time and skills required to explain why it may not be needed.[5] Current decision-making practices have acknowledged inadequacies,[9] and improving patients' involvement in making truly informed health decisions may improve the appropriate use of interventions.

Balancing the concerns about the overuse of interventions, at the other end of the spectrum, is underuse. Interventions with strong evidence of overall benefit can improve health outcomes only if patients commence and continue with them. Poor adherence to medical recommendations, particularly medication use, has been widely studied, with factors such as poor communication of intervention information contributing to it.[10] Underestimating the benefits and overestimating the harms of interventions may contribute to poor adherence to effective interventions.

Reports of individuals' (either patients or the general public) expectations about the likely benefit or harm of various interventions are fragmented across the literature. We aimed to systematically review all studies that had quantitatively measured patient or public expectations of the benefit and/or harm of any medical treatment, test, or screen.

Methods

Types of Studies, Participants, and Outcome Measures

All quantitative primary study designs were eligible. We had no restrictions about participant eligibility. Participants could, but did not need to, be planning to receive the intervention being studied.

We included studies in which participants were asked to provide a quantitative estimate of the expected benefits and/or harms of a treatment, test, or screen (a test conducted in people without disease signs or symptoms). Outcomes were eligible if they asked about the chance of the benefit or harm occurring and/or the size of it. Studies in which participants were asked to provide a descriptive estimate without any quantification (eg, "much better," "a little worse") and those that only measured expectations about the risk of having or developing a disease or condition were excluded.

Search Methods for Identification of Studies

We used a comprehensive search strategy consisting of a combination of subject heading terms, free text words, and wild cards and proximity operators to broaden search retrieval and searched MEDLINE (1946 through June 2013), Embase (1974 through June 2013), Cumulative Index to Nursing and Allied Health Literature (1981 through June 2013), and PsycINFO (1967 through June 2013). We developed the strategy in consultation with a medical librarian experienced in systematic reviews. Initial search terms were drawn from a small set of key articles. We used an iterative process of building a search strategy, running the search, scanning the relevant retrieved articles for additional terms, and then rebuilding the search strategy with the newly identified relevant terms and related subject headings. The final search strategy for MEDLINE (eAppendix in the Supplement) was adapted for each database. To identify additional published, unpublished, and ongoing studies, we (1) tracked relevant references through Web of Science's cited reference search, (2) scanned the reference lists of identified studies, (3) contacted experts and researchers in the field, and (4) posted a request to the international evidence-based health care listserv.

Study Selection

A review author (T.C.H.) and a research assistant screened the titles and abstracts of articles identified in the searches and by other methods and eliminated articles according to the inclusion criteria. We obtained the full texts of studies considered eligible from this process or for which eligibility was unclear. A research assistant and 1 author (T.C.H.) independently decided each trial's inclusion or exclusion. We resolved any disagreements by discussion, and when consensus could not be reached, the other author (C.D.M.) was consulted and a decision made.

Data Extraction and Assessment of Methodological Quality

Both of us (T.C.H., C.D.M.) independently completed a data extraction form to extract data and record the methodological quality of studies. Disagreements were resolved by discussion. Most included studies were a survey, and accordingly we extracted information relevant to key quality criteria for assessment of bias in surveys, namely, clear research question, sufficiently large and representative sampling method, outcome measures and/or instruments used, and response rate (ideally ≥60%)[11] (**Tables 1** and **2**). We extracted data for the outcomes and/or measures relevant to the review's purpose. For intervention studies (usually providing participants with information about the intervention being examined), we only included baseline data or, if a controlled trial, control group data. Where the authors of studies had provided a contemporaneous estimate of the benefits or harms of the intervention(s) and published this as the "correct" answer, we extracted this. For a number of studies, we contacted authors for additional data or to clarify study details.

Data Analysis

For studies that provided a correct answer about an intervention's benefits or harms, where possible, we extracted or calculated the proportion of participants who responded correctly or with an overestimation or underestimation. A meta-analysis was not possible because of the range of study designs and outcomes used.

Table 1. Details of Studies That Assessed Participants' Benefit and Harm Expectations of Treatment

Source	Study Purpose/ Method of Data Collection	Participants	Outcomes and/or Measures Relevant to Systematic Review Purpose	Authors' Conclusions
Baars et al,[12] 2009	To assess patients' perspective about benefit and risk of infliximab use/ Written survey, completed at clinic	152 patients (mean age, 38 y; 61% women) attending an inflammatory bowel disease outpatient clinic in the Netherlands (all patients invited during recruitment period)	Benefits of infliximab: remission rate after 1. 2 wk; 2. 1 y Risks of infliximab use compared with the general population: 3. risk of lymphoma compared to general population 4. risk of dying from a serious adverse effect	The majority of patients overestimated remission rates and underestimated risks of infliximab use
Bernstein et al,[13] 2012	To assess pregnant women's estimates of the risks and benefits of trial of labor after previous cesarean delivery/ Face-to-face survey	155 women admitted for delivery who were eligible for trial of labor after 1 previous cesarean delivery (87 for trial of labor; 68 who elected for repeat cesarean delivery) in 1 hospital in the US	1. Chance of success of trial of labor after previous cesarean delivery 2. Risk of uterine rupture during vaginal delivery	Women who are candidates for trial of labor after a previous cesarean delivery appear to know little about the risks and benefits of this mode of delivery
Coo et al,[14] 2001	To assess women's knowledge of HT/ Telephone survey	207 (75% response rate) female patients aged 45-64 y from 2 primary care practices in Canada	1. (Women at increased risk of heart disease) and 2. (women not at increased risk) How many of the 71 women would be protected against heart disease because they took HT? 3. (women at increased risk for osteoporosis) and 4. (women not at increased risk) How many of the 36 women would not break a hip because they took HT? 5. (women at increased breast cancer risk) and 6. (women not at increased risk) How many more women out of 100 would develop breast cancer because they took HT?	Many women overestimated the benefits of HT for hip fracture reduction and the potential increase of lifetime risk of breast cancer
Fagerlin et al,[15] 2010[a] and Hoffman et al,[16] 2010[a]	To determine adults' knowledge about information relevant to medication, screening, or surgery decisions they recently made (DECISIONS study)/ Telephone survey	2575 adults (39% male; weighted response rate of 51.6%) recruited for a random-digit dial survey of English-speaking US adults ≥40 y. Answered specific Q modules if they had undergone the particular treatment, screening, or surgery or discussed doing so with a health professional in the previous 2 y. Hoffman et al[16] present analysis of responses to cancer screening modules, for participants ≥50 y (n = 1082)—Qs 9 and 10 in this article	Out of 100 people who have __, about how many will have 1. knee/hip replacement, pain relief after surgery 2. lower back pain, benefit from back surgery 3. cataract surgery, improved vision 4. hip/knee replacement, complications 5. back surgery, complications 6. back surgery, same or worse pain after surgery 7. cataract surgery, still have to wear glasses after operation 8. cataract surgery, need a second procedure 9. How often does a high prostate specific antigen and 10. positive mammogram result in a cancer diagnosis?	Patient knowledge of key facts relevant to recently made medical decisions is often poor (Fagerlin et al[15]). Participants overestimated the positive predictive values of PSA tests and mammography (Hoffman et al[16])
Habib et al,[17] 2008	To explore benefit and risk perceptions of patients undergoing peripheral angioplasty and trial new information tool/ Face-to-face interview by consenting clinician after patients informed of procedure	200 patients undergoing peripheral angioplasty over a 12-mo period in UK. Mean age, 69 y; 67% male. Only half (100) the participants received the risk assessment tool.	"What do you think are the chances (percentage) you will benefit from today's procedure?"	Patients undergoing peripheral angioplasty tend to overestimate its benefits and underestimate its risks
Hudson et al,[18] 2012[a]	To assess patients' expectations of benefits of screening for breast and bowel cancer and medication to prevent hip fracture and cardiovascular disease/ Mailed survey	Convenience sample of 354 patients (36% response rate) aged 50-70 y registered with 3 general practices in New Zealand. Mean age, 60 y; 56% male	Of 5000 people aged 50-70 y __, how many __: 1. with osteoporosis, hip fractures would be prevented by taking medication for 10 y to reduce the risk of this? 2. screened for bowel cancer regularly for 10 y, deaths due to bowel cancer would be prevented by this screening? 3. given medication for 10 y to reduce risk of death from cardiovascular disease, how many deaths due to this prevented? 4. [women] screened for breast cancer regularly for 10 y, deaths due to breast cancer prevented by screening?	Patients overestimated the risk reduction achieved (overestimated benefit) with 4 examples of screening and preventative medications
Kee et al,[19] 1997	To describe cardiac patients' understanding of coronary angioplasty benefit/ Face-to-face interview by research nurse within 24 h of angiography consent and angioplasty consent	150 consecutively recruited (30 declined participation) patients undergoing elective coronary angioplasty at 2 regional cardiology centers in the UK	Patient estimates of 1. benefit to life expectancy (in years and months) 2. rate of major complications	Patients vastly overestimated the capacity of angioplasty to control their disease

(continued)

Table 1. Details of Studies That Assessed Participants' Benefit and Harm Expectations of Treatment (continued)

Source	Study Purpose/ Method of Data Collection	Participants	Outcomes and/or Measures Relevant to Systematic Review Purpose	Authors' Conclusions
Lee et al,[20] 2001	To measure patients' and physicians' expectations before stem cell transplant and correlate them with actual outcomes after transplant (only patients' data reported here)/ Mailed survey before transplant	313 patients (458 invited; 68% response rate) attending a tertiary care transplant center in the US and planning for autologous or allogeneic hematopoietic stem cell transplantation for hematologic disease within 3 mo (but not <1 wk) of study enrolment (median age, 47 y; 52% male)	1. "What do you think is your chance of being cured (a) with and (b) without a stem cell transplant?" 2. "What % of people do you think die during the transplant hospitalization or from complications within the first year?" (6 response options: almost all [>90%], most [75%-90%], majority [50%-74%], less than half [25%-49%], few [10%-24%], almost none [<10%])	Patients were fairly accurate at estimating mortality when actual mortality was <30%; beyond that they had overly optimistic expectations. Patient expectations of disease-free survival were high and constant regardless of disease stage
Lytsy et al,[21] 2007	To assess patients' expectations of the effect of statins and factors influencing this/ Postal survey distributed via pharmacists	829 (69% response rate) patients presenting a statin prescription at 1 of 27 pharmacies in Sweden. Mean age, 65 y; 54% male	"Imagine that one thousand individuals, with a similar health status as yours, receive the same lipid-lowering treatment as you for 5 years. How many of these patients do you believe would not suffer a heart attack compared to if they did not receive treatment?"	Patients overestimated the general effect of statins
Mancini et al,[22] 2006[a]	To assess impact of information booklet on women's decisions about genetic testing for BRCA1/2 mutation (only control group [not given booklet] data reported here)/ Survey distributed face-to-face at clinic and mailed back	Control group n = 263 (87% response rate) of consecutive women (mean age, 49 y) with personal history of breast cancer and the first in the family to consider BRCA1/2 analysis; recruited from 11 cancer genetic clinics in France	1. Estimated proportion of breast cancer *detected* in women <40 y old with a genetic predisposition to breast cancer by annual mammography from 30 y of age 2. Estimated proportion of breast cancer *prevented* by preventive mastectomy in women <40 y old with a genetic predisposition to breast cancer 3. Estimated proportion of ovarian cancer *prevented* by preventive ovariectomy in women with a genetic predisposition to ovarian cancer	Not specified (authors' conclusions were about the effect of the information booklet)
Metcalfe et al,[23] 2002	To compare perceptions of breast cancer risk in women who had undergone prophylactic bilateral mastectomy/ Mailed survey, with telephone contact before and after survey	75 (61% response rate) women who underwent bilateral mastectomy in any Ontario hospital in the previous decade. Mean (range) age, 48 (23-70) y. 60 women (80%) provided responses to risk Qs	Asked to estimate their own lifetime risk of developing breast cancer before and after they underwent the prophylactic mastectomy	Women who had preventative breast surgery significantly overestimated their lifetime risk of developing breast cancer (except those with BRCA1/2 gene mutations)
Ravdin et al,[24] 1998	To assess adjuvant chemotherapy expectations in women with nonmetastatic breast cancer/ Mailed survey	2660 breast cancer support group members in the US invited, 562 responded and a final sample of 318 eligible patients (nonmetastatic breast cancer and received adjuvant chemotherapy). Median age, 49 y	Participants asked to estimate their prognosis with and without adjuvant therapy. 216 (68%) gave estimates of prognosis	Women in the sample overestimated the value of adjuvant therapy
Schonwetter et al,[25] 1991	To assess knowledge of CPR in elderly veterans/ Face-to-face survey by an interviewer at clinic; telephone call 1-2 wk later	64 eligible (>74 y) veterans from an outpatient clinic in the US. Mean (range) age, 82 (75-95) y	Patients asked to estimate their chance (%) of 1. immediate survival after CPR and 2. survival to hospital discharge. (Only data from first interview reported here because patients were given CPR information before the second interview)	The sample consistently overestimated the chance of surviving CPR.
Siegel et al,[26] 2008	To determine patients' and parents' perceptions of risk and benefits of infliximab for IBD/ Written survey completed prior to a public lecture about IBD treatment	Convenience sample of 165 patients (or parents of patients) with IBD at 1 of 2 patient education symposiums in US. 53% were adult patients (median age, 46 y); 47% were parents (median age of children, 16 y); 68% female	Vignette given and asked, "If 100 similar patients with Crohn disease had the same symptoms and were treated with Remicade, how many patients out of those 100: 1. will improve in 2 wk because of the drug?" 2. will be in complete remission after 1 y of regularly taking the drug? 3. Compared to general population, what is the chance of the 35-year-old developing lymphoma after taking the drug for 1 y? 4. What is the chance of dying of a side effect of the drug?	Patients and parents of patients overestimate the benefit of infliximab use and underestimate the risks
Smith et al,[27] 2008	To examine benefit expectations on QOL in kidney transplant recipients/ Computer-assisted telephone interview, before and 1 y after transplant	307 (80% response rate) patients on a renal transplant waiting list in the US; 210 completed 1-y posttransplant interview. Mean age, 48 y; 59% male	Patients asked to rate 1. (Pretransplant) their current QOL (from 0 "worst" to 100 "best imaginable") 2. (Pretransplant) anticipated QOL 1 y after a successful transplant 3. (1 y after transplant) QOL	Patients substantially overestimated the benefits to QOL of a successful kidney transplant
Watson et al,[28] 1997	To investigate opinions of the elderly about CPR decisions/ Face-to-face semistructured interview at admission and at discharge	95 (96% response rate) eligible elderly patients in 1 hospital in New Zealand recruited from consecutive admissions over 5-wk period. Mean age, 80 y; 63% female	Patients asked what they thought the success rate of CPR was	Elderly patients wish to be consulted about CPR. Patients overestimated the success rate of CPR

Table 1. Details of Studies That Assessed Participants' Benefit and Harm Expectations of Treatment (continued)

Source	Study Purpose/ Method of Data Collection	Participants	Outcomes and/or Measures Relevant to Systematic Review Purpose	Authors' Conclusions
Wee et al,[29] 2006	To investigate patients' expectations for bariatric surgery/ Telephone survey	Convenience sample of 45 patients (60% response rate) planning bariatric surgery at 1 hospital in US. Mean age, 43 y; mean BMI, 47; 95% female	Patients estimated 1. the highest and 2. the lowest amount of weight they expected to lose from bariatric surgery	Patients have unrealistic weight loss expectations for bariatric surgery
Weymiller et al,[30] 2007	To evaluate a decision aid about statin drugs on treatment decision making (only control group [not given decision aid] data reported here)/ Self-administered written survey, completed straight after clinic visit	98 (99% response rate) patients with diabetes mellitus attending a metabolic clinic in US. Control group n = 46 (43 responses to risk estimation Q), with mean age, 66 y; 57% female	"If you think of 100 people like you, all of whom are taking a daily statin (cholesterol pill), how many do you think will have a heart attack in the next 10 years?" (5 response options)	Not specified (authors' conclusions were about the effect of the decision aid)

Abbreviations: BMI, body mass index (calculated as weight in kilograms divided by height in meters squared); CPR, cardiopulmonary resuscitation; IBD, inflammatory bowel disease; N/A, not available; Q, question; QOL, quality of life; UK, United Kingdom; US, United States.

[a] Study included treatment and screening.

Results

Studies Identified

We screened 15 343 studies (after removing duplicates) and discarded 15 252 after examining title and abstract. Of the remaining 91 full-text articles, 36 were eligible for inclusion (**Figure 1**), from 35 studies (2 articles were from the same study[15,16]).

Description of Studies

Characteristics of the studies are shown in Table 1 (studies about treatment) and Table 2 (tests and screens). In the Supplement, there is an expanded version of these tables (eTable 1 and eTable 2) that contains participants' responses to the questions about benefit and harm expectations, along with the "correct" estimate as provided by study authors. The earliest study was published in 1994,[43] and the most recent, in 2013.[47] Studies were from 16 countries, with the highest number (n = 17) from the United States. Study sample size ranged from 45[29] to 10 228.[38] Across the 35 studies, a total of 27 323 participants were involved. Across the 16 studies about treatments, there was a wide range of treatments (18) studied (Table 1), with only 4 (infliximab for inflammatory bowel disease,[12,26] cardiopulmonary resuscitation,[25,28] prophylactic mastectomy,[22,23] and statins for cardiovascular disease[21,30]) examined by more than 1 study. Of the 20 studies about tests or screening, 15 were concerned with cancer.

Fourteen (40%) studies focused on screening, 15 (43%) on treatment, 3 (9%) on a test, and 3 (9%) on both treatment and screening. More studies assessed just expectations of benefit (22 [63%]) than benefit and harm (10 [29%]) or just harm (3 [8%]). Across all studies, a total of 81 outcomes relevant to the review's purposes were used, with 54 outcomes assessing benefit expectations and 27 assessing harm expectations (eFigure in the Supplement shows this by intervention topic).

Most studies used multiple-choice questions to assess expectations (69% of outcomes); the remainder asked participants to provide a quantitative estimate (eg, "out of 1000 people, how many would…") without providing response options. The most frequent study design was a survey (face-to-face, telephone, or mailed). In some studies, data were collected from patients who had received, were about to receive, or were considering receiving the intervention of

interest.* In others, participants were sampled from people who were currently attending or had recently attended a health care facility[14,18,25,27,28,33,41,45] or from the general population.[31,34-36,38,44,46] The response rate was at least 60% in 17 of the 27 studies for which it could be determined. Three studies were randomized trials,[22,30,40] 1 was a nonrandomized trial,[17] and 2 were before-and-after studies,[25,28] in which the effect of providing information was being evaluated (only control group or baseline data for the relevant outcome were used).

Expectations of Benefit

Of the 32 studies that assessed expectations of benefit, 21 (37 outcomes) compared participants' responses with the study authors' "correct" estimates of benefit (**Figure 2**). The majority (≥50%) of participants overestimated benefit for 22 (65%) of the 34 outcomes for which overestimation data were provided. The proportion of participants who overestimated benefit ranged from 7% to 94%. A majority of participants provided correct estimation for only 2 outcomes: the proportion of people with improved vision after cataract surgery[15] and cervical smear test accuracy.[44] Underestimation of benefit by at least 50% of participants occurred for 1 outcome (benefit of back surgery on lower back pain).[10]

Seventeen outcomes (from 15 studies) are not shown in Figure 2 because for these, either the study authors did not provide a correct estimate of benefit or outcomes were measured in a way that did not enable the proportion of patients who provided a correct answer, overestimation, or underestimation to be calculated (eg, a mean estimate of benefit; see eTables 1 and 2 in the Supplement). For 15 (88%) of these outcomes, study authors provided comment in the article that participants overestimated the benefit of the intervention(s). For 1 outcome,[22] the authors reported that the correct answer was unknown and drew no conclusion about participants' responses.

Expectations of Harm

In 11 studies (25 outcomes), harm expectations were compared with a "correct" estimate of harm; at least 50% of participants underestimated the harm for 10 (67%)[12,15,19,26,47] of the 15 outcomes for which underestimation data were available (**Figure 3**). The proportion of participants who underestimated harm ranged from 18% to

*References 12, 13, 15-17, 19-24, 26, 27, 29, 32, 37, 39, 40, 43, 47

Table 2. Details of Studies That Assessed Participants' Benefit and Harm Expectations of Tests and Screening

Source	Study Purpose/ Method of Data Collection	Participants	Outcomes and/or Measures Relevant to Systematic Review Purpose	Authors' Conclusions
Barratt et al,[31] 1999	To investigate women's estimates of screening mammography accuracy and attitudes about compensation for missed cancers/ Telephone interview	115 (64% response rate) women from a national sample of women aged 30-69 y (mean, 46 y) in Australia	Estimate of how many of 100 women with early breast cancer would have it detected with screening mammography	Unrealistically high expectations of the sensitivity of screening mammography were common in this sample of women
Basama et al,[32] 2004	To assess women's perceptions of the 20-wk anomaly fetal scan and its limitations/ Survey completed at the unit, before the scan	385 (8% of total population attending over 3 mo) pregnant women presenting at 2 maternity units in the UK for a 20-wk ultrasound scan	Estimate of the percentage of fetal abnormalities that can be detected by the scan	There was an overestimation of the ability of the 20-wk scan to detect fetal abnormalities
Black et al,[33] 1995	To determine how women aged 40-50 y perceive their risk of breast cancer and effectiveness of screening/ Mailed survey	145 (73% response rate) women aged 40-50 y randomly sampled from 1 university medical center in the US. All had been billed for a Papanicolaou test recently and had not been hospitalized or visited the center more than twice in 6 mo	Of 1000 women like you, how many will, in the next 10 y, die from breast cancer 1. if not screened for it by mammography or physician's examination; and 2. if screened for it by mammography or physician's examination[a]	Many women younger than 50 y substantially overestimate their breast cancer risk and the effectiveness of screening
Chamot and Perneger,[34] 2001	To assess accuracy of women's perceptions about mortality reduction from mammography screening/ Mailed survey	895 (72% response rate) women aged 40-80 y and free of breast cancer randomly selected from a population registry in Switzerland	"Does mammography screening prevent death from breast cancer in women aged over 50?"	Most women were uninformed about and overestimated the efficacy of mammography screening
Cockburn et al,[35] 1995	To estimate the public's understanding of screening and its benefits and limitations/ Telephone interview	835 participants of a representative sample of the English-speaking Australian population aged 18-70 y; 51% male	Asked about the accuracy (by estimating the percentage of cases detected) of 1. the Papanicolaou test 2. mammography	The public have misconceptions about the purpose of screening and the accuracy of screening tests
Domenighetti et al,[36] 2003	To assess women's understanding of benefits of mammography screening/ Computer-assisted telephone interview	4140 (69% response rate of those eligible) women aged ≥15 y selected by random telephone digit dialing in the UK, US, Italy, and Switzerland	1. To what extent can mammography reduce breast cancer deaths in women ≥50 y screened every 2 y for 10 y? 2. How many deaths due to breast cancer can be prevented among 1000 women aged ≥50 y who have mammography every 2 y for 10 y?	A high proportion of women overestimated the benefits of mammography screening
Gekas et al,[37] 1999	To estimate information needs of pregnant women during screening for Down syndrome/ Survey completed by participants at the clinic	200 women (40% response rate) from population of pregnant women attending for amniocentesis at a university hospital in France. Women were younger than 38 y with a positive serum marker after a maternal serum screening	"What percentage of miscarriage may be induced by amniocentesis?"	Many participants overestimated the risk of amniocentesis, despite extensive counseling
Gigerenzer et al,[38] 2009	To estimate the public's knowledge of the benefits of screening for breast and prostate cancer/ Face-to-face computer-assisted interviews in participants' homes	10 228 (60% response rate) participants of a random sample, stratified to be representative of the populations of 9 European countries. Age distribution: 14-19 y (8%), 20-29 y (17%), 30-39 y (18%), 40-49 y (18%), 50-59 y (15%), 60-69 y (12%), ≥70 y (12%)	1. (women only asked) If 1000 women ≥40 y are screened for breast cancer by mammography every 2 y for 10 y, after 10 y how many fewer women who had the screening die from breast cancer compared to those who did not? 2. (men only asked) If 1000 men ≥50 y are screened for prostate cancer (by PSA test) every 2 y, after 10 y how many fewer men who had the screening die from prostate cancer compared to those who did not?	The vast majority overestimate the benefits of mammography and PSA screening
Groves et al,[39] 2004	To assess patients' perceptions of the benefits and risks of myocardial perfusion scintigraphy/ Face-to-face interview with the physician before and after investigation	Convenience sample (recruited over 2-mo period) of 90 patients undergoing thallium-201 myocardial perfusion study at a university hospital in the UK. Mean (range) age, 64 (31-90) y; 56% female	Prior to the procedure, patients were asked about their chance of benefit (%) from it[b]	Many patients lack knowledge of the risks of myocardial perfusion scintigraphy
Haakenson et al,[40] 2006	To assess impact of intervention to improve women's knowledge of mammography screening (only control group data reported here)/ Mailed survey	248 in the control group (34% response rate) of a convenience sample of 648 women scheduled for mammography within 4 wk at a clinic in the US. Mean age, 61 y	1. What percentage of deaths from breast cancer are reduced by mammography? 2. What percentage of women will need to return for additional mammograms after the screening mammogram? 3. Of the women who return, what percentage will need biopsies after the extra mammogram? 4. Of all biopsies, what percentage of abnormalities detected by mammogram will not be cancerous?	Not specified (authors' conclusions were about the effect of the information booklet)

(continued)

Table 2. Details of Studies That Assessed Participants' Benefit and Harm Expectations of Tests and Screening (continued)

Source	Study Purpose/ Method of Data Collection	Participants	Outcomes and/or Measures Relevant to Systematic Review Purpose	Authors' Conclusions
Haggstrom and Schapira,[41] 2006	To assess racial differences in perception of risk of breast cancer survival and screening mammography benefit/ Written survey completed in person at the clinic	254 (18% response rate) women 40-85 y (mean, 55 y) randomly sampled from 2 general internal medicine academic clinics in the US. Excluded if breast cancer history, dementia, or <2 y life expectancy	For women your age, how much do you think regular mammograms decrease the risk of dying from breast cancer? (5 response options: not at all, 5%-25%, 26%-50%, 51%-75%, 76%-100%)	Awareness of risk perceptions can help physicians tailor patient education
Lewis et al,[42] 2003	To assess effect of providing information about mammography benefits and harms on screening perception/ Survey completed face to face at clinic (prior to receiving intervention) (only baseline data reported here)	Convenience sample (55% response rate) of 179 women aged 35-49 y from a general internal medicine academic clinic in the US (excluded if breast cancer history or unable to read and write English)	Out of 1000 women who have yearly mammograms for 10 y, how many 1. live longer because of screening? 2. would have a false positive? 3. would be upset by a false positive even after they knew there was nothing wrong? (response options not clearly specified)	Women strongly perceived that mammography benefits outweighed the harms; and giving accurate information had no effect on these perceptions
Neptune et al,[43] 1994	To assess baseline knowledge of risk of IV contrast material for diagnostic radiology/ Written survey completed while at outpatient clinic	147 (98% response rate) consecutive outpatients, in US, undergoing CT (n = 109) or urogram (n = 41) requiring IV contrast material. 68% had previous IV contrast radiology, 54% male, 47% >55 y	The chance of (4 response options for each Q) 1. a minor reaction from IV contrast material 2. a serious reaction from the injection of contrast material 3. dying from the injection of contrast material	Information regarding the risks of IV contrast material cannot be considered common knowledge among patients
Philips et al,[44] 2003	To explore beliefs and perceptions of cervical cancer and its screening among university students/ Survey sent through university internal mail	Convenience sample (44% response rate) of 222 female students aged 18-23 y (mean, 19 y) attending a university in the UK	1. How many cases of cervical cancers are prevented in the UK each year by a cervical screening program? 2. How accurate is the cervical smear test?	Most participants overestimated the incidence of cervical cancer prevented, had some inaccurate knowledge about the screening program, and had distorted beliefs about the power of screening
Phillips et al,[45] 2005	To estimate women's knowledge of cervical cancer, risk factors, and efficacy of screening/ Survey distributed at general practices for return by post or to the practice	1244 (28% response rate) women eligible for cervical screening attending for routine (nonscreening) consultations with a general practitioner at 20 practices in the UK	1. How many cases of cervical cancers are prevented in the UK each year by a cervical screening program? 2. How accurate is the cervical smear test?	Women typically overestimate both the incidence of cervical cancer and the efficacy of screening
Schwartz et al,[46] 2000	To determine women's attitudes to and knowledge of false-positive mammography results and detection of ductal carcinoma in situ after screening mammography/ Mailed survey	479 eligible (65% response rate) women (18-97 y) who did not report a history of breast cancer) randomly selected from telephone directories in US	Visual analogue scale (Q1, 2): 1. For a 60-year-old woman who has yearly mammograms for 10 y, what is the chance she will have a false alarm where one mammogram will look like she has cancer even when she doesn't? 2. In a healthy 60-year-old woman who has breast cancer and no other symptoms, what is the chance a mammogram will find the cancer? 3. If this woman had yearly mammograms for the next 10 y, how much would it change her chance of dying of breast cancer?	Women are aware of false-positive results and view them as acceptable consequences of screening mammography. Most are unaware that screening can detect cancers that may not progress
Sin et al,[47] 2013	To investigate patients' awareness of radiation dose and associated risks of radiological procedures/ Face-to-face survey, completed by participants while at the hospital	173 private and public patients randomly sampled (200 patients invited, 87% response rate) undergoing a diagnostic radiology procedure at 1 Hong Kong hospital. Mean (range) age, 53 (21-83) y; 48% male	1. the risk of inducing a fatal cancer from CT for adults 2. the amount of radiation you receive from a CT is equivalent to that received from how many chest radiographs?	Most patients underestimated the fatal cancer risk of CT scanning and many underestimated risk of CT compared with chest radiography. Patient radiation awareness is unsatisfactory

Abbreviations: CT, computed tomography; IV, intravenous; PSA, prostate-specific antigen; Q, question; QOL, quality of life; UK, United Kingdom; US, United States.

[a] Qs also asked for "in the next 20 y," but results were not provided in the article.

[b] Also asked whether they thought there would be pain, radiation, and adverse effects, but quantification of risk was not assessed and data were not eligible.

97%. There was correct harm estimation by at least 50% of participants for only 2 outcomes: the proportion of people who still need glasses after cataract surgery[15] and miscarriage risk from amniocentesis.[37] Overestimation of harm by at least 50% of participants occurred for only 1 outcome (increased breast cancer risk from hormone therapy in healthy women).[14]

Expectations Summarized by Intervention Topic
Cancer—Screening
Fifteen studies (29 outcomes) examined cancer screening—breast,† cervical,[35,44,45] prostate,[16,38] and bowel.[18] Most (23 [79%]) outcomes assessed benefit expectations, with the proportion of par-

†References 16, 18, 22, 31, 33-36, 38, 40-42, 46

ticipants correctly responding ranging from 2% to 77%. For 13 (65%) of the 20 benefit outcomes that were compared with a correct answer, benefit was overestimated by at least 50% of participants. All 6 harm outcomes were about mammography, with the proportion of correct responses ranging from 9% to 20%.

Cancer—Treatment and Risk-Reducing Surgery

Studies examined risk-reducing surgery,[22,23] stem cell transplantation,[20] and adjuvant chemotherapy for breast cancer.[24] One measured benefit and harm expectations[20]; 3 measured only benefit expectations. One study[22] provided the proportion of correct responses (33%, 26%), whereas the remainder[20,23,24] presented mean estimates of benefit and concluded that participants overestimated benefit. For the 1 harm outcome (mortality related to stem cell transplantation treatment[20]), the majority underestimated it.

Cardiovascular Disease—Prevention and Management

Five studies (6 outcomes) measured expectations about use of medication for preventing cardiovascular disease,[18,21,30] coronary angioplasty,[19] or peripheral angioplasty.[17] Five outcomes assessed benefit expectations: for one, 28% responded correctly[30]; for another, 28% of participants responded correctly and 69% overestimated benefit[18]; the other 3[17,19,21] reported benefits as mean (or median) benefit and concluded that participants overestimated benefit. For the 1 harm outcome,[19] 27% of participants answered correctly and 55% underestimated the risk of major complications of coronary angioplasty.

Surgery

In addition to the cardiovascular surgery studies reported in the subsection on cardiovascular disease, 3 studies (10 outcomes) assessed surgery expectations—orthopedic and eye,[15] renal transplant,[27] and bariatric surgery.[29] For the 5 benefit outcomes, 3[15] were reported as the proportion of correct responses (25%, 28%, 61%) and 2 as mean estimated benefit,[27,29] which the authors concluded were overestimates. For the 5 harm outcomes,[15] correct responses ranged from 13% to 56%, with harm underestimated by the majority for 3.

Medication

In addition to the medication studies summarized in other subsections, 17 outcomes (4 studies) measured medication expectations: infliximab for inflammatory bowel disease,[12,26] hormone therapy,[14] and medication to prevent hip fracture in osteoporosis.[18] Ten outcomes assessed benefit, with correct response rates ranging from 10% to 34% of participants and at least 50% of participants overestimating benefit in 8 outcomes. Of the 7 harm outcomes, correct response rates ranged from 2% to 37%, with harm underestimated by at least 50% of participants for 5 outcomes.

Fetal and Maternal Medicine

Of the 4 outcomes (3 studies), 2 measured benefit expectations, with a low proportion of correct responses: 9% (trial of labor after previous cesarean delivery[13]) and 8% (fetal abnormality scan; 90% overestimated benefit of scan[32]). Of the 2 harm outcomes, 38% (trial of labor[13]) and 57% of participants (amniocentesis risk[37]) provided a correct response.

Figure 1. Flow of the Information Through the Phases of the Review
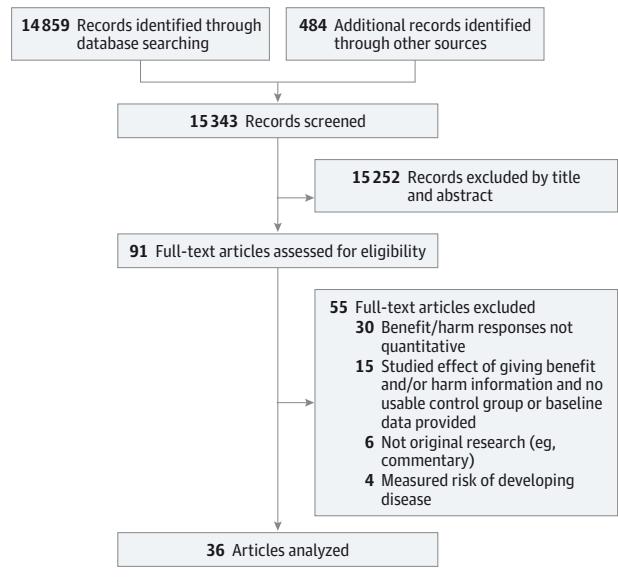
Diagnostic Radiology Procedures

Expectations were measured in 2 studies[43,47] with 5 outcomes. All addressed harm, and correct responses ranged from 18% to 48%, with authors concluding that many participants underestimated harms.

Cardiopulmonary Resuscitation

Two studies (3 outcomes) assessed benefit expectations[25,48] and reported mean estimated success rates, with authors concluding that participants overestimated the success rate.

Discussion

To our knowledge, this is the first systematic review of patient or public expectations of the benefits and harms of medical interventions. Participants rarely had accurate expectations of benefits and harms, and for many interventions, regardless of whether a treatment, test, or screen, they had a tendency to overestimate its benefits and underestimate its harms.

Strengths of this review include its lack of restrictions on language or study design, contact with authors for additional data, and diversity in the interventions and countries included. However, this diversity means that there is sufficient heterogeneity in the way expectations were measured to preclude calculation of summary estimates of the size of overestimates and underestimates. For some studies, we could not calculate the proportion of participants who provided correct answers, overestimates, or underestimates. In others, authors did not provide quantitative information regarding what they considered to be the correct answer yet obviously had an "answer" in mind when drawing conclusions. In studies in which authors did provide a correct estimate, we took their estimates at face value and did not attempt to verify whether these answers were based on the best evidence available at the time of that study. In at least 1 study, trial evidence[49] subsequently overturned 1 "correct"

Figure 2. Proportion of Participants Providing a Correct Estimate, Underestimate, or Overestimate of Intervention Benefit
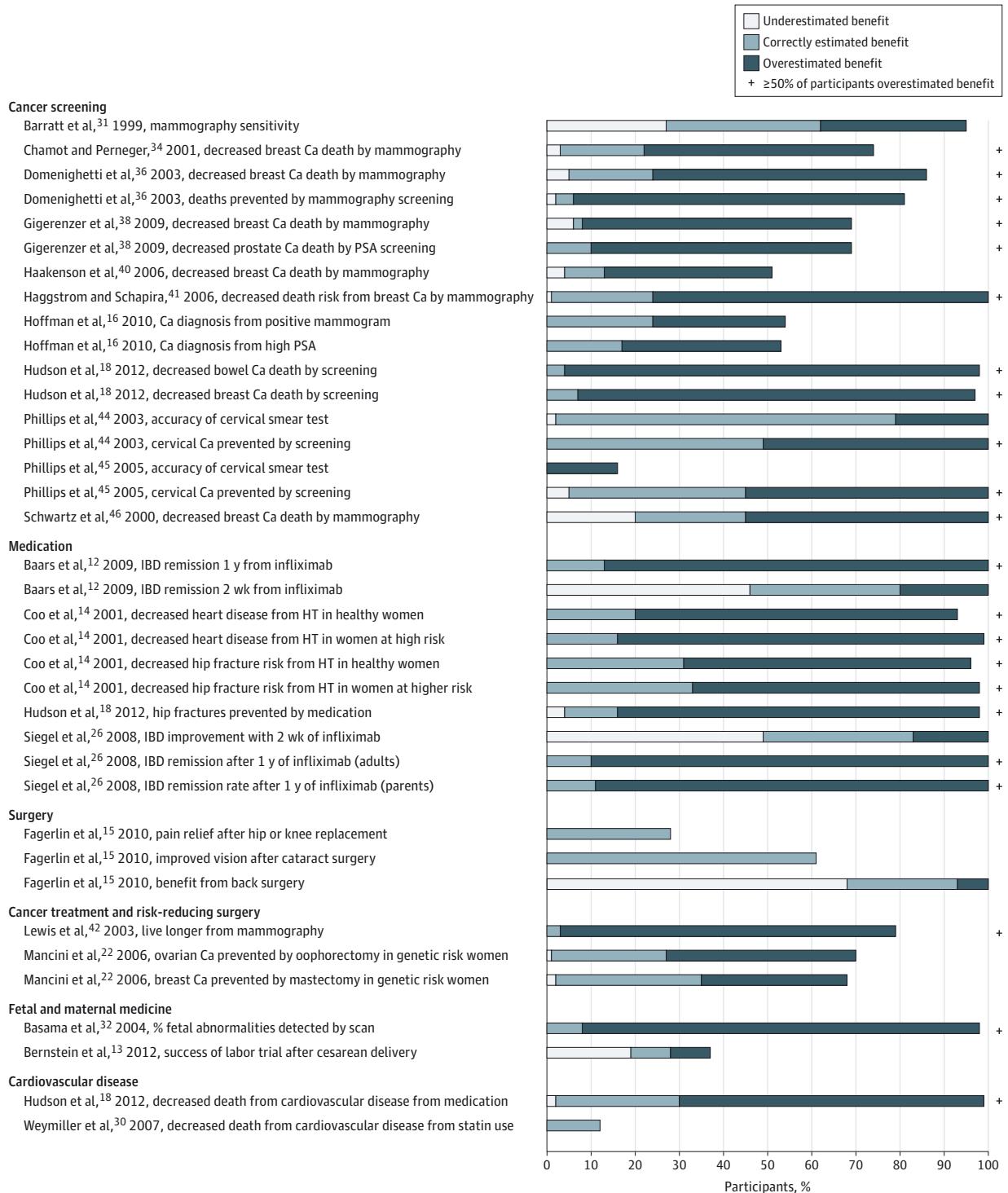
Ca indicates cancer; HT, hormone therapy; IBD, irritable bowel disease; PSA, prostate-specific antigen.

answer (hormone therapy is protective against cardiovascular disease).[14] Some studies had small and/or selective samples, and the measures used to assess participants' expectations were largely untested. The impact on expectations from asking participants at various stages of intervention consideration (not considering, considering, already received it) or from using various methods of eliciting expectations, with some questions asking about personal benefit and/or harm (eg, what are *your* chances…) and others about population benefit and/or harm (eg, out of 1000 people, how many…), is not clear.

Figure 3. Proportion of Participants Providing a Correct Estimate, Underestimate, or Overestimate of Intervention Harm

Legend:
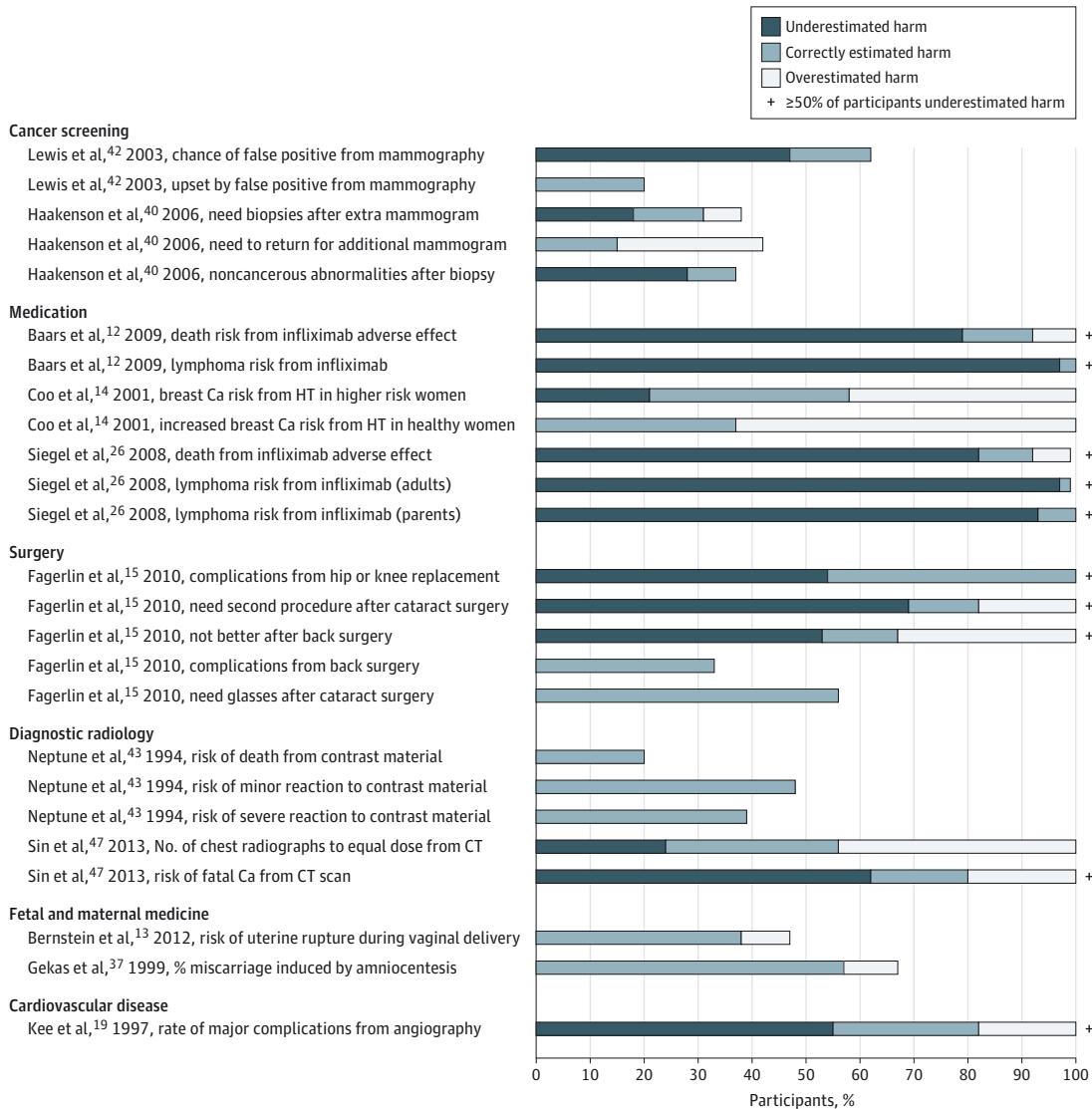- Underestimated harm
- Correctly estimated harm
- Overestimated harm
- +   ≥50% of participants underestimated harm

Cancer screening
- Lewis et al,[42] 2003, chance of false positive from mammography
- Lewis et al,[42] 2003, upset by false positive from mammography
- Haakenson et al,[40] 2006, need biopsies after extra mammogram
- Haakenson et al,[40] 2006, need to return for additional mammogram
- Haakenson et al,[40] 2006, noncancerous abnormalities after biopsy

Medication
- Baars et al,[12] 2009, death risk from infliximab adverse effect   +
- Baars et al,[12] 2009, lymphoma risk from infliximab   +
- Coo et al,[14] 2001, breast Ca risk from HT in higher risk women
- Coo et al,[14] 2001, increased breast Ca risk from HT in healthy women
- Siegel et al,[26] 2008, death from infliximab adverse effect   +
- Siegel et al,[26] 2008, lymphoma risk from infliximab (adults)   +
- Siegel et al,[26] 2008, lymphoma risk from infliximab (parents)   +

Surgery
- Fagerlin et al,[15] 2010, complications from hip or knee replacement   +
- Fagerlin et al,[15] 2010, need second procedure after cataract surgery   +
- Fagerlin et al,[15] 2010, not better after back surgery   +
- Fagerlin et al,[15] 2010, complications from back surgery
- Fagerlin et al,[15] 2010, need glasses after cataract surgery

Diagnostic radiology
- Neptune et al,[43] 1994, risk of death from contrast material
- Neptune et al,[43] 1994, risk of minor reaction to contrast material
- Neptune et al,[43] 1994, risk of severe reaction to contrast material
- Sin et al,[47] 2013, No. of chest radiographs to equal dose from CT
- Sin et al,[47] 2013, risk of fatal Ca from CT scan   +

Fetal and maternal medicine
- Bernstein et al,[13] 2012, risk of uterine rupture during vaginal delivery
- Gekas et al,[37] 1999, % miscarriage induced by amniocentesis

Cardiovascular disease
- Kee et al,[19] 1997, rate of major complications from angiography   +

x-axis: Participants, %   (0, 10, 20, 30, 40, 50, 60, 70, 80, 90, 100)

Ca indicates cancer; CT, computed tomography; HT, hormone therapy.

Overly optimistic intervention expectations by patients and the public are undoubtedly contributing to the growing problem of overdiagnosis and overtreatment. This medical optimism has many likely drivers, caused by influences within and beyond the patient-clinician interaction. The relationship between optimistic bias (in which individuals perceive that they are at less risk than their peers)[50] and intervention expectations is not clear. Having unrealistic intervention expectations may enable patients to meet some psychological needs, such as hope, safety, a sense of control, action, and reassurance.[51] If patients believe that interventions are effective (which this review suggests that they largely do), they are likely to request the interventions from their clinicians.[52,53] The point of consultation with a clinician presents an opportunity for education and correction of misperceptions about effectiveness. Yet these opportunities may be missed: clinicians are often poor at detecting expectations specific to the patient visit[54] and may avoid asking direct questions about expectations to circumvent confrontation.[55] Even once clinicians are aware of patient expectations, managing them well can be difficult. A heavy impact of patient expectations and requests has been described by physicians, with approximately half of requests fulfilled only because the patient asked, despite the physicians feeling uncomfortable about some of them.[52] In a survey of US physicians, 36% indicated that they would order unnecessary investigations because of patient expectations.[56]

Clinicians' contributions to patients' overly optimistic expectations may range from a failure to detect and correct them to contributing (either actively or by omission) to their development or reinforcement. Clinicians themselves may have overly optimistic expectations about the benefits of interventions[57,58] and poor knowledge of harms[59] and may oversell interventions when offering them to patients.[60] Interventions may be recommended with the best of intentions—reflecting a tendency for clinicians to emphasize *doing*

rather than *not doing* as a habitual response to health threats and to try anything for distressed patients, however poor the evidence of effectiveness[61] or even after identifying no benefit.[58] In the absence of supporting empirical evidence, clinicians' decisions to provide an intervention may be overinfluenced by a belief in the pathophysiological effectiveness of the intervention's mechanism of action.[62,63] Alternatively, clinicians may be unaware of the true effectiveness or benefit-harm trade-off, or there may be other influences, such as the lack of incentive for discouraging patients from proceeding with an intervention[58] or pecuniary interests, including fee-for-service.[5,64]

The sometimes misleading and inaccurate portrayal of intervention benefit in messages from many commercial sources (such as the pharmaceutical industry[65]), health services (such as cancer centers[66] and screening services[67,68]), and the media[69-72] also undoubtedly contributes to the development of overly optimistic expectations in patients and clinicians. A contributor to patients' underestimates of intervention harms may be the lack of attention given to communicating them. This is commonplace and widespread—occurring in the media,[69-72] cancer center advertisements,[66] screening invitations,[67,68] and direct-to-consumer prescription advertising,[65] and even by clinicians. In an evaluation of what physicians in the United States tell patients about screening harms, only 9.5% of patients were informed about the possibility of overdiagnosis and overtreatment during a conversation about cancer screening, yet 80% wanted to be told of these harms before being screened.[59] Clinicians' poor knowledge of intervention harms is unsurprising because, compared with benefits, harms are much less routinely evaluated and reported in both primary research studies[73,74] and, consequently, systematic reviews.[75] In this review's studies, two-thirds assessed only benefit expectations.

Ironically, one of the influencing factors on clinicians' decisions to provide interventions (even with limited or no benefit) is patients' expectations.[52,58,62] In turn, because the requested interventions are often provided, patients' assumptions that they are beneficial and necessary are reinforced.[58] Breaking this positive feedback loop is crucial. Shared decision making is a logical process for achieving this. It is a process in which a clinician and patient jointly participate in making a health decision, having discussed the options and their benefits and harms and considered the patient's values, preferences, and circumstances.[76] It provides the opportunity for clinicians to elicit patients' expectations and present accurate and balanced information about the benefits and harms of each option. Evidence-informed discussions can help patients to construct informed preferences.[77]

Communicating both the benefits and harms of interventions to patients may play a key role in dampening their enthusiasm for some interventions. Studies have reported that many participants indicated that they would stop, or not commence, screening if they knew that screening harms were high or outweighed the benefits.[59,78] Decision aids are one tool that can be used to facilitate shared decision making and communication about benefits and harms; and if they include probability information, they can improve risk perception accuracy. Decision aid use can also sometimes reduce intervention uptake[79]—for example, following decision aid use, people are less likely to choose major elective surgery and undergo prostate-specific antigen screening.[79]

Beyond decision aids, other initiatives may help to provide individuals with accurate and balanced information. Examples include the Drug Facts Box[80] and the Choosing Wisely campaign.[81] The Drug Facts Box clearly presents the benefits and harms of prescription drugs and may improve the accuracy of individuals' expectations of medication use.[82] The Choosing Wisely initiative provides evidence-based information for the public about interventions that are commonly used yet may be unnecessary or cause harm. It encourages clinicians and patients to discuss these interventions so that informed decisions can be made.[81]

Clinicians can play a major role in facilitating less use of interventions by patients.[53] For example, they can invite patients to participate in decisions about interventions—which the majority want to do[83,84]—and ensure that they are sufficiently skilled in facilitating shared decision making and aware of resources that can assist.[76] However, shared decision making is yet to become routine[85]; there are many barriers to its widespread implementation, including the need for it to be embedded in clinician training,[86] workflows and systems, and culture.[87-89] Shared decision making also provides a mechanism to overcome the failings of traditional informed consent practices,[90] to achieve truly informed consent.

Whereas overly optimistic patient expectations are undoubtedly contributing to intervention overuse, operating in the opposite direction is the possibility that overestimation of intervention benefit may be a contributor to adherence,[91] even if this is based on unfounded optimism. Hence, for interventions needed by patients on an ongoing basis, communication and decisions need to strike a delicate balance between providing accurate information about benefits and harms and avoiding compromising adherence.[92] In this situation also, shared decision making, particularly for patients with chronic illnesses, can assist with achieving agreement about a treatment plan and consequently adherence.[10,93]

Conclusions

The importance of this review's findings relates to the appetite that people have for medical interventions. Many want to have more and resist having less.[53,94] Unless this is countered by accurate and balanced information, it will continue to be a driver for more intervention use than benefits society.

REFERENCES

1. Martin AB, Lassman D, Washington B, Catlin A; National Health Expenditure Accounts Team. Growth in US health spending remained slow in 2010; health share of gross domestic product was unchanged from 2009. *Health Aff (Millwood)*. 2012; 31(1):208-219.

2. Lipitz-Snyderman A, Bach PB. Overuse of health care services: when less is more … more or less. *JAMA Intern Med*. 2013;173(14):1277-1278.

3. Korenstein D, Falk R, Howell EA, Bishop T, Keyhani S. Overuse of health care services in the United States: an understudied problem. *Arch Intern Med*. 2012;172(2):171-178.

4. Moynihan R, Doust J, Henry D. Preventing overdiagnosis: how to stop harming the healthy. *BMJ*. 2012;344:e3502.

5. Grady D, Redberg RF. Less is more: how less health care can result in better health. *Arch Intern Med*. 2010;170(9):749-750.

6. Pickering TG. Now we are sick: labeling and hypertension. *J Clin Hypertens (Greenwich)*. 2006; 8(1):57-60.

7. Ogedegbe G. Labeling and hypertension: it is time to intervene on its negative consequences. *Hypertension*. 2010;56(3):344-345.

8. Moses H III, Matheson DHM, Dorsey ER, George BP, Sadoff D, Yoshimura S. The anatomy of health care in the United States. *JAMA*. 2013;310(18):1947-1963.

9. Krumholz HM. Variations in health care, patient preferences, and high-quality decision making. *JAMA*. 2013;310(2):151-152.

10. Brown MT, Bussell JK. Medication adherence: WHO cares? *Mayo Clin Proc*. 2011;86(4):304-314.

11. Boynton PM, Greenhalgh T. Selecting, designing, and developing your questionnaire. *BMJ*. 2004;328(7451):1312-1315.

12. Baars JE, Siegel CA, Kuipers EJ, van der Woude CJ. Patient's perspectives important for early anti-tumor necrosis factor treatment in inflammatory bowel disease. *Digestion*. 2009;79 (1):30-35.

13. Bernstein SN, Matalon-Grazi S, Rosenn BM. Trial of labor versus repeat cesarean: are patients making an informed decision? *Am J Obstet Gynecol*. 2012;207(3):e1-e6.

14. Coo H, O'Connor KS, Hunter D. Women's knowledge of hormone therapy. *Patient Educ Couns*. 2001;45(4):295-301.

15. Fagerlin A, Sepucha KR, Couper MP, Levin CA, Singer E, Zikmund-Fisher BJ. Patients' knowledge about 9 common health conditions: the DECISIONS survey. *Med Decis Making*. 2010;30(5)(suppl):35S-52S.

16. Hoffman RM, Lewis CL, Pignone M, et al. Decision-making processes for breast, colorectal, and prostate cancer screening: the DECISIONS survey. *Med Decis Making*. 2010;30(5)(suppl):53S-64S.

17. Habib SB, Sonoda L, See TC, Ell PJ, Groves AM. How do patients perceive the benefits and risks of peripheral angioplasty? implications for informed consent. *J Vasc Interv Radiol*. 2008;19(2, pt 1):177-181.

18. Hudson B, Zarifeh A, Young L, Wells JE. Patients' expectations of screening and preventive treatments. *Ann Fam Med*. 2012;10(6):495-502.

19. Kee F, McDonald P, Gaffney B. Risks and benefits of coronary angioplasty: the patients perspective: a preliminary study. *Qual Health Care*. 1997;6(3):131-139.

20. Lee SJ, Fairclough D, Antin JH, Weeks JC. Discrepancies between patient and physician estimates for the success of stem cell transplantation. *JAMA*. 2001;285(8):1034-1038.

21. Lytsy P, Westerling R. Patient expectations on lipid-lowering drugs. *Patient Educ Couns*. 2007;67 (1-2):143-150.

22. Mancini J, Noguès C, Adenis C, et al. Impact of an information booklet on satisfaction and decision-making about BRCA genetic testing. *Eur J Cancer*. 2006;42(7):871-881.

23. Metcalfe KA, Narod SA. Breast cancer risk perception among women who have undergone prophylactic bilateral mastectomy. *J Natl Cancer Inst*. 2002;94(20):1564-1569.

24. Ravdin PM, Siminoff IA, Harvey JA. Survey of breast cancer patients concerning their knowledge and expectations of adjuvant therapy. *J Clin Oncol*. 1998;16(2):515-521.

25. Schonwetter RS, Teasdale TA, Taffet G, Robinson BE, Luchi RJ. Educating the elderly: cardiopulmonary resuscitation decisions before and after intervention. *J Am Geriatr Soc*. 1991;39(4): 372-377.

26. Siegel CA, Levy LC, Mackenzie TA, Sands BE. Patient perceptions of the risks and benefits of infliximab for the treatment of inflammatory bowel disease. *Inflamm Bowel Dis*. 2008;14(1):1-6.

27. Smith D, Loewenstein G, Jepson C, Jankovich A, Feldman H, Ubel P. Mispredicting and misremembering: patients with renal failure overestimate improvements in quality of life after a kidney transplant. *Health Psychol*. 2008;27(5):653-658.

28. Watson DR, Wilkinson TJ, Sainsbury R, Kidd JE. The effect of hospital admission on the opinions and knowledge of elderly patients regarding cardiopulmonary resuscitation. *Age Ageing*. 1997; 26(6):429-434.

29. Wee CC, Jones DB, Davis RB, Bourland AC, Hamel MB. Understanding patients' value of weight loss and expectations for bariatric surgery. *Obes Surg*. 2006;16(4):496-500.

30. Weymiller AJ, Montori VM, Jones LA, et al. Helping patients with type 2 diabetes mellitus make treatment decisions: statin choice randomized trial. *Arch Intern Med*. 2007;167(10):1076-1082.

31. Barratt A, Cockburn J, Furnival C, McBride A, Mallon L. Perceived sensitivity of mammographic screening: women's views on test accuracy and financial compensation for missed cancers. *J Epidemiol Community Health*. 1999;53(11):716-720.

32. Basama FM, Leonard B, Leighton M. Audit: women's perception and knowledge of the 20 weeks anomaly scan. *J Obstet Gynaecol*. 2004;24 (1):44-46.

33. Black WC, Nease RF Jr, Tosteson AN. Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. *J Natl Cancer Inst*. 1995;87(10):720-731.

34. Chamot E, Perneger TV. Misconceptions about efficacy of mammography screening: a public health dilemma. *J Epidemiol Community Health*. 2001;55(11):799-803.

35. Cockburn J, Redman S, Hill D, Henry E. Public understanding of medical screening. *J Med Screen*. 1995;2(4):224-227.

36. Domenighetti G, D'Avanzo B, Egger M, et al. Women's perception of the benefits of mammography screening: population-based survey in four countries. *Int J Epidemiol*. 2003;32(5):816-821.

37. Gekas J, Gondry J, Mazur S, Cesbron P, Thepot F. Informed consent to serum screening for Down syndrome: are women given adequate information? *Prenat Diagn*. 1999;19(1):1-7.

38. Gigerenzer G, Mata J, Frank R. Public knowledge of benefits of breast and prostate cancer screening in Europe. *J Natl Cancer Inst*. 2009;101(17):1216-1220.

39. Groves AM, Kayani I, Syed R, Gacinovic S, Nagabushan N, Ell PJ. Myocardial perfusion scintigraphy: patients' perception of benefit and risk. *Nucl Med Commun*. 2004;25(12):1219-1222.

40. Haakenson CP, Vickers KS, Cha SS, et al. Efficacy of a simple, low-cost educational intervention in improving knowledge about risks and benefits of screening mammography. *Mayo Clin Proc*. 2006;81(6):783-791.

41. Haggstrom DA, Schapira MM. Black-white differences in risk perceptions of breast cancer survival and screening mammography benefit. *J Gen Intern Med*. 2006;21(4):371-377.

42. Lewis CL, Pignone MP, Sheridan SL, Downs SM, Kinsinger LS. A randomized trial of three videos that differ in the framing of information about mammography in women 40 to 49 years old. *J Gen Intern Med*. 2003;18(11):875-883.

43. Neptune SM, Hopper KD, Matthews YL. Risks associated with the use of IV contrast material: analysis of patients' awareness. *AJR Am J Roentgenol*. 1994;162(2):451-454.

44. Philips Z, Johnson S, Avis M, Whynes DK. Human papillomavirus and the value of screening: young women's knowledge of cervical cancer. *Health Educ Res*. 2003;18(3):318-328.

45. Philips Z, Avis M, Whynes DK. Knowledge of cervical cancer and screening among women in east-central England. *Int J Gynecol Cancer*. 2005;15 (4):639-645.

46. Schwartz LM, Woloshin S, Sox HC, Fischhoff B, Welch HG. US women's attitudes to false positive mammography results and detection of ductal carcinoma in situ: cross sectional survey. *BMJ*. 2000;320(7250):1635-1640.

47. Sin HK, Wong CS, Huang B, Yiu KL, Wong WL, Chu YC. Assessing local patients' knowledge and awareness of radiation dose and risks associated with medical imaging: a questionnaire study. *J Med Imaging Radiat Oncol*. 2013;57(1):38-44.

48. Watson E, Hewitson P, Brett J, et al. Informed decision making and prostate specific antigen (PSA) testing for prostate cancer: a randomised controlled trial exploring the impact of a brief patient decision aid on men's knowledge, attitudes and intention to be tested. *Patient Educ Couns*. 2006;63(3):367-379.

49. Rossouw JE, Anderson GL, Prentice RL, et al; Writing Group for the Women's Health Initiative Investigators. Risks and benefits of estrogen plus progestin in healthy postmenopausal women: principal results from the Women's Health Initiative randomized controlled trial. *JAMA*. 2002;288(3):321-333.

50. Weinstein ND. Unrealistic optimism about susceptibility to health problems: conclusions from a community-wide sample. *J Behav Med*. 1987;10(5):481-500.

51. Woolf SH. The price of false beliefs: unrealistic expectations as a contributor to the health care crisis. *Ann Fam Med*. 2012;10(6):491-494.

52. Keitz SA, Stechuchak KM, Grambow SC, Koropchak CM, Tulsky JA. Behind closed doors: management of patient expectations in primary care practices. *Arch Intern Med*. 2007;167(5):445-452.

53. Herndon MB, Schwartz LM, Woloshin S, et al. Older patients perceptions of "unnecessary" tests and referrals: a national survey of Medicare beneficiaries. *J Gen Intern Med*. 2008;23(10):1547-1554.

54. Rao JK, Weinberger M, Kroenke K. Visit-specific expectations and patient-centered outcomes: a literature review. *Arch Fam Med*. 2000;9(10):1148-1155.

55. Mustafa M, Wood F, Butler CC, Elwyn G. Managing expectations of antibiotics for upper respiratory tract infections: a qualitative study. *Ann Fam Med*. 2014;12(1):29-36.

56. Campbell EG, Regan S, Gruen RL, et al. Professionalism in medicine: results of a national survey of physicians. *Ann Intern Med*. 2007;147(11):795-802.

57. Sapre N, Mann S, Elley CR. Doctors' perceptions of the prognostic benefit of statins in patients who have had myocardial infarction. *Intern Med J*. 2009;39(5):277-282.

58. Rothberg MB, Sivalingam SK, Ashraf J, et al. Patients' and cardiologists' perceptions of the benefits of percutaneous coronary intervention for stable coronary disease. *Ann Intern Med*. 2010;153(5):307-313.

59. Wegwarth O, Gigerenzer G. Overdiagnosis and overtreatment: evaluation of what physicians tell their patients about screening harms. *JAMA Intern Med*. 2013;173(22):2086-2087.

60. Barratt AL, Glasziou PP. Do the benefits of screening mammography outweigh the harms of

overdiagnosis and unnecessary treatment? *Med J Aust*. 2012;196(11):681.

61. Doust J, Del Mar C. Why do doctors use treatments that do not work? *BMJ*. 2004;328 (7438):474-475.

62. Lin GA, Dudley RA, Redberg RF. Cardiologists' use of percutaneous coronary interventions for stable coronary artery disease. *Arch Intern Med*. 2007;167(15):1604-1609.

63. Prasad V, Ho N. Why do we continue to adopt medical practices based on pathophysiology alone when we should be insisting on clinical trials? *J Clin Epidemiol*. 2014;67(4):361-363.

64. Emanuel EJ, Fuchs VR. The perfect storm of overutilization. *JAMA*. 2008;299(23):2789-2791.

65. Woloshin S, Schwartz LM, Tremmel J, Welch HG. Direct-to-consumer advertisements for prescription drugs: what are Americans being sold? *Lancet*. 2001;358(9288):1141-1146.

66. Vater LB, Donohue JM, Arnold R, White DB, Chu E, Schenker Y. What are cancer centers advertising to the public?: a content analysis. *Ann Intern Med*. 2014;160(12):813-820.

67. Gummersbach E, Piccoliori G, Zerbe CO, et al. Are women getting relevant information about mammography screening for an informed consent: a critical appraisal of information brochures used for screening invitation in Germany, Italy, Spain and France. *Eur J Public Health*. 2010;20(4):409-414.

68. Jørgensen KJ, Gøtzsche PC. Content of invitations for publicly funded screening mammography. *BMJ*. 2006;332(7540):538-541.

69. Moynihan R, Bero L, Ross-Degnan D, et al. Coverage by the news media of the benefits and risks of medications. *N Engl J Med*. 2000;342(22):1645-1650.

70. Cassels A, Hughes MA, Cole C, Mintzes B, Lexchin J, McCormack JP. Drugs in the news: an analysis of Canadian newspaper coverage of new prescription drugs. *CMAJ*. 2003;168(9):1133-1137.

71. Schwitzer G. Addressing tensions when popular media and evidence-based care collide. *BMC Med Inform Decis Mak*. 2013;13(suppl 3):S3.

72. Schwitzer G. A guide to reading health care news stories. *JAMA Intern Med*. 2014;174(7):1183-1186.

73. Jørgensen KJ, Klahn A, Gøtzsche PC. Are benefits and harms in mammography screening given equal attention in scientific articles? a cross-sectional study. *BMC Med*. 2007;5:12.

74. Heleno B, Thomsen MF, Rodrigues DS, Jørgensen KJ, Brodersen J. Quantification of harms in cancer screening trials: literature review. *BMJ*. 2013;347:f5334.

75. Zorzela L, Golder S, Liu Y, et al. Quality of reporting in systematic reviews of adverse events: systematic review. *BMJ*. 2014;348:f7668.

76. Hoffmann TC, Légaré F, Simmons MB, et al. Shared decision making: what do clinicians need to know and why should they bother? *Med J Aust*. 2014;201(1):35-39.

77. Hoffmann TC, Montori VM, Del Mar C. The connection between evidence-based medicine and shared decision making. *JAMA*. 2014;312(13):1295-1296.

78. Torke AM, Schwartz PH, Holtz LR, Montz K, Sachs GA. Older adults and forgoing cancer

screening: "I think it would be strange." *JAMA Intern Med*. 2013;173(7):526-531.

79. Stacey D, Légaré F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2014;1:CD001431.

80. Schwartz LM, Woloshin S, Welch HG. Using a drug facts box to communicate drug benefits and harms: two randomized trials. *Ann Intern Med*. 2009;150(8):516-527.

81. Cassel CK, Guest JA. Choosing wisely: helping physicians and patients make smart decisions about their care. *JAMA*. 2012;307(17):1801-1802.

82. Schwartz LM, Woloshin S. The Drug Facts Box: improving the communication of prescription drug information. *Proc Natl Acad Sci U S A*. 2013;110(suppl 3):14069-14074.

83. Alston C, Paget L, Halvorson G, et al. *Communicating With Patients on Health Care Evidence: Discussion Paper*. Washington, DC: Institute of Medicine; 2012.

84. Coulter A, Jenkinson C. European patients' views on the responsiveness of health systems and healthcare providers. *Eur J Public Health*. 2005;15(4):355-360.

85. Couët N, Desroches S, Robitaille H, et al. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument [published online ahead of print March 4, 2013]. *Health Expect*. doi: 10.1111/hex.12054.

86. Hoffmann TC, Bennett S, Tomsett C, Del Mar C. Brief training of student clinicians in shared decision making: a single-blind randomized controlled trial. *J Gen Intern Med*. 2014;29(6):844-849.

87. King J, Moulton B. Group Health's participation in a shared decision-making demonstration yielded lessons, such as role of culture change. *Health Aff (Millwood)*. 2013;32(2):294-302.

88. Elwyn G, Scholl I, Tietbohl C, et al. "Many miles to go ...": a systematic review of the implementation of patient decision support interventions into routine clinical practice. *BMC Med Inform Decis Mak*. 2013;13(suppl 2):S14.

89. Légaré F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Aff (Millwood)*. 2013;32(2):276-284.

90. Krumholz HM. Informed consent to promote patient-centered care. *JAMA*. 2010;303(12):1190-1191.

91. Marshall IJ, Wolfe CD, McKevitt C. Lay perspectives on hypertension and drug adherence: systematic review of qualitative research. *BMJ*. 2012;345:e3953.

92. Trewby PN, Reddy AV, Trewby CS, Ashton VJ, Brennan G, Inglis J. Are preventive drugs preventive enough? a study of patients' expectation of benefit from preventive drugs. *Clin Med*. 2002;2(6):527-533.

93. Joosten EA, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CPF, de Jong CA. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychother Psychosom*. 2008;77(4):219-226.

94. Schwartz LM, Woloshin S, Fowler FJ Jr, Welch HG. Enthusiasm for cancer screening in the United States. *JAMA*. 2004;291(1):71-78.