



Making decisions about breast reconstruction: A systematic review of patient-reported factors influencing choice

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Abstract

Purpose Many studies have explored women's reasons for choosing or declining a particular type of breast reconstruction (BR) following mastectomy for breast cancer. This systematic review synthesises women's reasons for choosing a range of BR options, including no BR, in different settings and across time.

Methods Thirteen databases were systematically searched, with 30 studies (4269 participants), meeting the selection criteria. Information on study aim and time frame, participation rate, design/methods, limitations/bias, reasons and conclusions, as well as participant clinical and demographic information, was reported. An overall quality score was generated for each study. Reasons were grouped into eight domains.

Results While study methodology and results were heterogeneous, all reported reasons were covered by the eight domains: Feeling/looking normal; Feeling/looking good; Being practical; Influence of others; Relationship

expectations; Fear; Timing; and Unnecessary. We found a strong consistency in reasons across studies, ranging from 52% of relevant publications citing relationship expectations as a reason for choosing BR, up to 91% citing fear as a reason for delaying or declining BR. Major thematic findings were a lack of adequate information about BR, lack of genuine choice for women and additional access limitations due to health system barriers.

Conclusions Understanding women's reasons for wanting or not wanting BR can assist clinicians to help women make choices most aligned with their individual values and needs. Our thematic findings have equity implications and illustrate the need for surgeons to discuss all clinically appropriate BR options with mastectomy patients, even if some options are not available locally.

Keywords Breast cancer · Breast reconstruction · Patient-reported outcome measures · Quality of life · Reasons

Background

One in eight Australian women will develop breast cancer and approximately 30% will require mastectomy [1]. Having the option of breast reconstruction (BR) has a positive impact on the quality of life of many women with breast cancer, including improved psychological well-being, body image, vitality, femininity and sexuality [2–9]. A few studies, however, have reported either no significant differences in particular outcomes for women with or without BR [10, 11], or significant aesthetic dissatisfaction with BR outcomes in women with post-operative complications [12].

Not all women requiring or choosing mastectomy will want BR [13] and individual women have their own reasons for choosing immediate BR (IBR), delayed BR (DBR)

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or no BR (NBR). Several studies have investigated the predictors of BR. Factors associated with an increased likelihood of BR uptake in Australia include higher socioeconomic status and levels of health insurance coverage [14], less remote geographic location [15], younger age, non-Indigenous status and less co-morbidity [16], higher levels of education, having children, not requiring radiotherapy [17] and less distance to travel [18]. In other nations, studies have associated higher rates of BR with a stronger self-concept of body image (France [19] and Switzerland [20]), a focus on appearance (Hong Kong [21]), younger age (United States of America (USA) [22], United Kingdom (UK) [23] and Switzerland [20]), depression (UK [23]), the role of partners (Japan [24]), and the influence of the surgeon (England [25]). Being of white race has been shown to be strongly associated with increased uptake of BR in the United States [26–28].

Understanding these predictors is useful for planning health services, but a more personal understanding of the decision making process is needed to support individual women to make a choice that is most aligned with their own values and needs so they can minimise the likelihood of decisional regret [29, 30]. Women considering BR following mastectomy for breast cancer face a potentially difficult choice that involves weighing up oncological, practical and personal factors at a very stressful time. Some women will want to make this decision on their own, others with the help of loved ones or clinicians [21, 31–33]. Some women will find the decision much easier than others [34, 35], some may not want to discuss all options [20, 25] and some may have unrealistic expectations [36, 37].

This systematic review has two aims. The first is to explore women's preferences regarding BR. Understanding how and why women come to their decision will help health professionals better support them through the decision-making process. It will also help to inform the development of specific educational strategies for consumers and health professionals (including plastic, breast and oncoplastic breast surgeons and breast care nurses) who discuss the options with patients undergoing mastectomy.

The second aim is to test the reliability of a set of domains used in a previous study to categorise women's reasons for their choice of BR [37]. This review assessed the suitability of these domains for a much larger and more diverse population of women considering BR following mastectomy for breast cancer.

Methodology

This study is part of a larger project investigating various aspects of BR. The literature search, therefore, was initially

broad and for this specific study was narrowed to articles relevant to decision-making/reasons for choice.

The following databases were searched: Australasian Medical Index; ATSI Health; Cochrane Central Register of Controlled Trials; Cochrane Database of Systematic Reviews; Cochrane Database of Effect; Cochrane Health Technology Assessment; Embase, Health & Society; Informat Health Collection; Medline; Medline In-Process (Premedline); PsycInfo; Rural Health. Articles published up until 29 February 2016 were identified using the following search criteria: Initial general search terms were: ("breast cancer" OR "ductal carcinoma in situ" OR "mastectomy") AND "breast reconstruction". Specific search terms were as follows: "reason*" OR "choice*" OR "motivat*" OR "preference*" OR "access*" OR "decision*" OR "patient reported outcomes measure*" OR "PROM*". Articles were imported into an Endnote library.

Inclusion criteria were original studies reporting: mastectomy for DCIS or invasive cancer AND immediate, delayed or no breast reconstruction AND implant or autologous breast reconstruction AND included patient-reported information about reasons for choice.

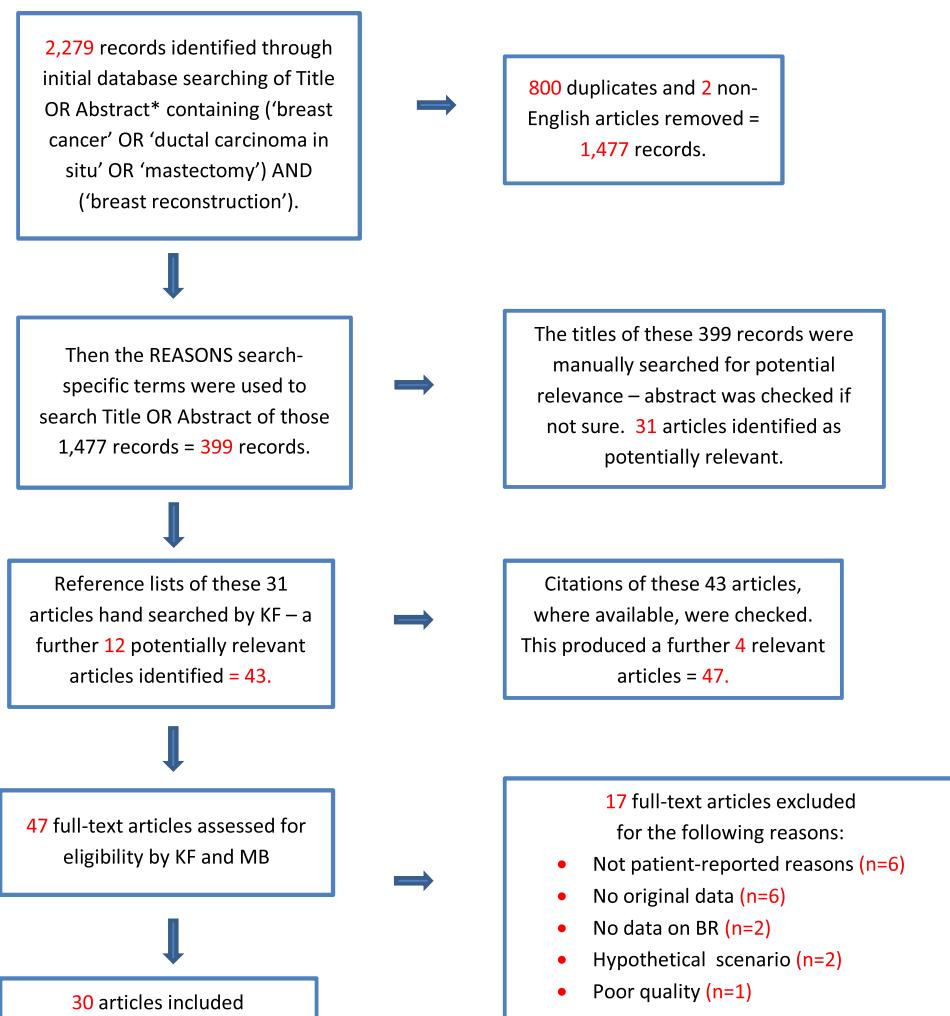
Exclusion criteria were as follows: studies of prophylactic mastectomy only; comparison of BCS and mastectomy only; review articles containing no original data; articles containing information about predictors of BR, or factors associated with BR, without patient-reported reasons for choice; abstracts without full text details; articles not written in English.

Figure 1 illustrates the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework used in this review. All studies satisfying the selection criteria were included, the first relevant publication dating back to 1979. References from included publications were checked, and citations of the original publications were also checked where available. Abstracts from these publications were reviewed by KF and MB to ensure they satisfied the selection criteria. Thirty studies were included in the review.

Assessment of quality

Study quality was assessed using an amended quality assessment tool for qualitative studies from the Alberta Heritage Foundation for Medical Research [38] (see Online Resource 1). This tool is appropriate for evaluating studies that are mostly descriptive (or level III studies using Daly et al.'s terminology) [39]. Questions related to the verification procedures and reflexivity were replaced because we are reviewing patient-reported responses, rather than assessing the objectivity of the authors (see Online Resource 2). Justification for our amendments is included with the Online Resource 2. Each paper was independently

Fig. 1 Systematic review process using an adaptation of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) schema



* To identify relevant articles that do not contain an abstract.

rated by two authors (KF and MB) on 12 items and allocated a score out of 24 (a higher score reflecting better quality). KF and MB then reviewed the independent ratings and agreed on a consensus quality score for each publication.

Classification into domains

Women's reasons for choosing to have or decline BR were categorised into eight domains as previously described [37]. This earlier prospective study used modified statements from Reaby's 1998 article [34] to compile three separate questionnaires asking why women chose IBR, DBR or NBR. Analysis of the 69 statements was simplified by categorising them into eight domains, based on pragmatic consensus views of the investigators and the findings suggested that they were appropriate for that study population [37].

For this systematic review, these original domains were refined slightly from the earlier study to ensure coverage of

all reasons identified in this review. Titles of the domains "feeling normal" and "feeling good" were amended to "feeling/looking normal" and "feeling/looking good" and the "expectations" title was amended to "relationship expectations" to differentiate these reasons from cosmetic or functional expectations.

Results

Studies included in the review

Table 1 provides an overview of the 30 included studies, including study aim and time frame, recruitment and study setting, number of participants and participation rate, design/methods, tools used, limitations/bias, reasons, conclusions and overall quality score. It shows a predominance of studies from the US ($n=11$), with four from Australia, two each from Japan, France, England and the Netherlands

Table 1 Overview of included studies

Author (year) [Ref.]	Journal	Country	Study aim	Study year	Number who participated	Participation rate
Adachi et al. (2007) [24] ^a	Jap J Clin Oncol	Japan	1. Clarify factors affecting choice of BCS, Mx only, Mx + IBR 2. If IBR chosen, the effect of body image and sexuality on that decision 3. Elucidate factors influencing psych adaptation after surgery	Not stated	103	50%
Alderman et al. (2011) [40]	Ann Surg Oncol	USA	To describe proportion of post-mx women who have BR; to evaluate factors contributing to decision to have IBR, DBR or NBR; to assess satisfaction with surgical decision	July 2007–Nov 2008	384	60.20%
Ananian et al. (2004) [19] ^b	Ann Surg Oncol	France	To measure women's decisions about BR & factors contributing to decision in context with SDM and maximum patient autonomy	Jan 2000–Jan 2002	181 (147 BR)	72.10%
BCNA (2011) [41] ^c	BCNA Breast Reconstruction Survey	Australia	To learn about barriers which reduce women's access to BR surgery and women's satisfaction with BR outcomes	Oct–10	462 completed all questions	42%
Begum et al. (2011) [25]	Pat Educ & Counsel	England	To examine patients' experiences of the decision to have BR	2007	21	70%
Clifford (1979) [43] ^f	Book chapter	USA	To examine the motivations and reactions of women who undergo BR	Not stated. Serial order	65	100%
Contant et al. (2000) [44] ^c	Pat Educ & Counsel	Netherlands	To evaluate patients' motivations for, and satisfaction with, treatment and information about IBR with silicone implants	1990–1995	73	71%
Duggal et al. (2013) [45]	Ann Plast Surg	USA	To investigate and improve our understanding of women's motivations for choosing BR	Dec 2008–Sept 2010	155	N/A
Elder et al. (2005) [46]	Breast	Sweden	To assess quality of life before and 12 months after Mx for breast cancer	Aug 1998–July 2001	76	92% Pre-op; 88% post-op; 81% both pre-op and post-op
Flitcroft et al. (2016) [37]	Psycho-Oncology	Australia	To evaluate reasons for choice of IBR, DR or NBR by women with high-risk BC	July 2013–Dec 2014	51 + RFR data from 4 women who did not require PMRT	94%
Gopie et al. (2011) [47]	JPRAS	Netherlands	To understand women's motives for choosing implant versus DIEP	Dec 2007–Jan 2009	31	66%
Handel et al. (1990) [22] ^b	PRS	USA	To evaluate why some Mx patients elect to have BR and others do not.	Oct 1991–July 1988	158: 71 with BR (69%); 87 with no recon (61%)	64%
Héquet et al. (2013) [48]	Springer Plus	France	To investigate factors associated with not having BR & to assess patient satisfaction with information on BR	Jan 2004–Feb 2007	61	61.4% of questionnaires returned. Only 61 completed = 46.2%
Keith et al. (2003) [23] ^b	PRS	UK	To identify characteristics of women with newly diagnosed BC and to evaluate perceived benefits and disadvantages of BR	Not stated	125—62 wanted BR; 53 don't (doesn't add up)	Not stated - ? perhaps its 115/125 = 92%
Lam et al. (2005) [21] ^b	Psycho-Oncology	China	To identify factors influencing Chinese women's choices between BCS, Mx only or Mx with BR	Oct 2001–Jan 2003	198	44.70
Lardi et al. (2013) [20] ^b	EJSO	Switzerland	To explore reasons for low uptake of DBR	1998–2009	101	89.40
Lee et al. (2010) [32] ^f	Ann Plast Surg	USA	To identify patients' goals and concerns that were important to their decisions about BR	2010	65	N/A
Manne et al. (2016) [35]	Cancer Nursing	USA	To describe women's reasons to choose or not choose BR, BR knowledge, decisional preparedness and decisional conflict	Not stated	55	? 56.7

Table 1 (continued)

Author (year) [Ref.]	Journal	Country	Study aim	Study year	Number who participated	Participation rate
Merejja and Siuominen (2005) [49]	Scandinavian J Surg	Finland	To evaluate the demand for plastic operations and increase knowledge on factors affecting wish for BR	Sept 2001–Aug 2002	84	76%
Morrow et al. (2014) [26] ^b	JAMA Surg	USA	To examine correlates of BR and to determine if a significant unmet need exists	Women diagnosed July 1 2005 – Feb 28 2007	485 final analytic survey	Baseline: 73%; Follow-up: 68%; Overall: 49% Not stated ?100%
Neill et al. (1988) [31]	Psychosocial Nursing Care	USA	To describe women's perspectives on factors that influenced decision to have BR	Not stated	11	
Nelson et al. (2013) [33]	JPRAS	USA	To examine delayed autologous BR to better understand reasons to delay BR	2005–2009	70	41
Nozawa et al. (2015) [50]	Int J Clin Oncol	Japan	To identify factors influencing decision to have BR, and identify influences of BR on patient behaviour and psych well-being	Jan 2011–June 2011	316 (but adds up to 358)	75.10
Panieri et al. (2003) [51]	The American Surgeon	South Africa	To determine proportion of patients suitable for BR after Mx, to determine how many accepted it and reasons for NOT accepting it	10 month period	83, 32 accepted BR; 51 declined	Not clear. Audit of all who declined NBR (51), but more ended up having NBR (69). 83 out of 135 'suitable' patients offered BR: = 61.5% participation rate
Reaby (1998) [34]	PRS	Australia	To gain greater understanding of why women choose to have BR or not, and of the difficulty in making that decision	1986–1992	95	50.5% response rate; 47.5% participation rate
Rowland et al. (1993) [52] ^c	Psychosomatics	USA	To evaluate prospectively a large cohort of women seeking BR and to assess the impact of these procedures on post-Mx adaptation and functioning	May 1980–Dec 1982	83	71% of those who had BR
Schain et al. (1985) [53]	Am J Psychiatry	USA	To evaluate the psychological adjustment of Mx patients who had immediate versus delayed BR	Oct–Nov 1981	63	70
Shameem et al. (2008) [29]	Asian Pac J Cancer Prevention	Malaysia	To determine the reasons why patients choose to have or not have (IBR	2000–2005	136	Not stated
Somogyi et al. (2015) [54]	Breast	Australia	To identify the factors that influence a woman's decision whether or not to have BR and to better understand their attitudes towards BR	Not stated	501–323 (65%) unilateral; 178 (35%) bilateral	68% of respondents (35.5% of those initially offered)
Zielinski (2014) [55]	Polski Przeglad Chirurgiczny	Poland	To investigate reasons why women are not likely to undergo recon following Mx for BC	1987–2013	73	N/A
Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Adachi et al. (2007) [24] ^a	Retrospective questionnaire with Likert scale, on relative importance	Constructed their own 8 item questionnaire based on the 'Breast Cancer Decision-Making Q'	Not controlled for age. IBR group younger; recall bias. Participation figures don't add up	Choice of Mx, BCS or IBR. Examines eight "value estimates of BR decision-making", rather than reasons. (1) Cancer cure & recurrence; (2) physical appearance; (3) positive r/ship with physician; (4) physician's judgement; (5) self-evaluation of femininity & sexuality; (6) attractiveness to partner; (7) positive r/ship with partner; (8) partner's judgement	IBR group valued physical appearance & attractiveness to partner significantly more than Mx or BCS groups; IBR valued positive r/ship with partner significantly more than Mx; Mx & BCS valued partner's judgements significantly more than IBR. This study suggests the importance of discussing body image and sexuality that has tended to be disregarded in Japan	17

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Alderman et al. (2011) [40]	Retrospective questionnaire	Questionnaire looked at body image, pragmatic concerns, sexuality, patient-reported physician concerns, patient concerns about treatment outcomes, patient treatment priorities; access barriers to reconstruction	Limited to two metro areas - Detroit and LA; recall bias; possible response bias - non-responders more disadvantaged. Type of BR not discussed	Three primary factors drive DBR and NBR: BR a low priority; uncertainty about possible complications and interference with surveillance; and less informed. Both IBR and DBR motivated by body image and practical concerns; IBR more concerned with sexuality; Few patients reported physician concern about having BR. Body image (feel whole, feel) as before cancer, feel attractive; Pragmatic concerns (wear same clothing, avoid prosthesis). Sexuality (more attractive to significant other; feel less self-conscious during sex)	About half of DBR had BR within 12 months - suggests high demand but perhaps lack of info or encouragement to consider IBR. Low SES patients less likely to be counselled about BR options and are less likely to have IBR or DBR. NBR - low priority, focus on cancer. Very few reported access barriers. Modest uptake of BR following initial cancer treatment. Those without recon demonstrated significant informational needs, which should be addressed	21
Ananian et al. (2004) [19] ^b	Prospective. Two decisions: (1) Mx with or without BR. (2) IBR versus DBR. Surgeons guessed patient response	Quality of Life (QoL): EORTC C30 & BR23. Depression CES-D scale. Plus their own 4 item 'fear of surgery' questionnaire and their own set of yes-no questions about d-m process	If women chose BR, surgeon decided type and timing, so women do not have 'maximum autonomy' as authors state. No major selection bias assumed by authors because a comparable IBR % was observed in the excluded group (who didn't complete surveys pre-op)	Factors correlated with BR, rather than reasons. Patients asked to choose between Mx only, IBR or DBR. In context of maximum autonomy, 81% chose BR. Of these women, 83% chose IBR and 17% DBR. Reasons for BR: psychosocial characteristics' body image, fear of surgery, and to get rid of prosthesis. Responses to actual questions not provided	Self-conception of body image is an important predictor for choosing BR. IBR preferred over DBR. No significant correlations between preferences for timing of BR and sociodemographic characteristics or approach to decision-making. Surgeons best source of medical info. Partners the most frequent source of non-medical advice.	22
BCNA (2011) [42] †	Retrospective online questionnaire	Not stated	No clinical or demographic data, although full survey results are referenced. Not representative population. Recall bias	Reasons for NBR: Decided not to have BR 51 (36%); can't afford cost of private surgery 39 (28%); still considering options 36 (26%); not a priority for me right now 34 (24%); currently on waiting list 18 (13%); ineligible for BR due to BC treatments 10 (7%); waiting times too long 8 (6%). BR not offered in my area 5 (3.6%); partner and/or family did not want me to have it 3 (2%); wasn't aware I could have it 3 (2%). Open comments: too much to deal with at time of Mx, don't want more surgery (if younger, would consider it), recovery period, lifestyle interruption and fear of outcome	Need for more info and to reduce out of pocket costs and waiting times. BCNA were going to develop a position statement on BR "outlining BCNA's view that women should be able to access affordable, timely, quality breast recon and that they should receive sufficient info about BR options to enable them to make informed decisions."	15

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Begum et al. (2011) [25]	Retrospective interviews - some by phone, some face to face	Developed their own based on previous studies and discussion with a plastic surgeon. Not strictly followed	DBR women did not make a real choice (not offered IBR); recall bias. No percentages or ranking of reasons provided	Reasons for BR: Avoid a period of being without a breast; body image, sense of own identity; maintain femininity; remove reminder of cancer; feel normal; surgeon's reputation; surgeon's confidence in outcome; surgeon's authority Reasons for IBR: Practical; one op not more - less pain, recovery time, less time off work, financial implications, caring for young children; also a few noted lack of choice - that's what the hospital does Reasons for DBR: Largely lack of choice - not suitable for IBR or not offered it because hospital didn't do it. Prostheses inconvenient and uncomfortable, limits clothing options	IBR and DBR had different reasons, and women are not always offered a choice. Surgeon's experience and reputation was the key influencing factor. Women considering BR should be provided with all the relevant information to make a well informed decision. Some women seek information and others avoid it, so need to tailor info delivery to individuals	18
Clifford (1979) [25] ^f	Retrospective interviews	Open ended 'psychologic' interviews. Asked women to share experiences and feelings about BC, Mx and recon	Recall bias a large problem. Individual reasons listed within each category (but no percentages provided). Only 4 DBRs, so analysis not possible	Asked about 'expectations' in 8 categories: restoration (69%), relief of clothing or prosthetic problems (49%); becoming less self-conscious or embarrassed (42%); improving appearance (40%); improving feelings (15%); improving marital relationships (15%); changing life-style (5%); no expectations (3%)	Search for restitution did not represent an adaptive failure because the woman had not adjusted to her appearance status. Women appeared to be reality oriented and were seeking to achieve normalcy through the rejection of a physical disability that may be remedial. Drive was clearly restorative and they did not, for the most part, seek to solve an inner problem or emotional turmoil	18
Contant et al. (2000) [44] ^f	Prospective & retrospective. Information modules and questionnaire explained. If they consented, given info modules pre-op. Another pre-op visit to discuss recommended surgical treatment. Sent questionnaire at least one year post-op	Some questions from prior research, some from existing scales and some constructed for the study	Women not given free choice but had discussion about "recommended surgical treatment"; did not report on quality of life, body image or sexual functioning results per say, only how they correlated with IBR satisfaction; recall bias. Not sure that distinction between motivations and advantages is meaningful.	Patients given six statements about their motivations for IBR and asked to agree or disagree: 97% to endure the amputation more easily; 93% to not have an external prosthesis; 89% to not be mutilated by the Mx; 80% to feel feminine again; 75% to remain sexually attractive; 67% to avoid changes in sexual relations. Patients also given 11 statements about their perceived advantages of IBR and asked to agree or disagree: 87% to not have an external prosthesis; 70% to feel feminine again; 70% to avoid changes in sexual relation; 69% to have an unchanged sexual relation with the partner; 69% to have the feeling of having something of one's own again; 66% to have more confidence; 63% to wear a bra when desirable; 61% to stay sexually active; 57% to feel oneself again; 50% to get rid of the cancer; 44% to endure the amputation more easily	Despite 50% of reconstructions resulting in "complications or complaints", 70% of women were satisfied with recon and only 12% would never choose IBR again. The more satisfied with IBR, fewer psychological complaints; correlation lower for physical complaints; the more a patient accepted her body, the more satisfied she was. High complication rate of 58%; 38% of women had higher expectations of IBR; 57% wanted more info re silicone implants, despite oral and written info being provided. Satisfaction rate was strongly inversely correlated with need for info - more info about BR needed	14

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Duggal et al. (2013) [45]	Prospective survey & literature review of BR	Survey statements developed from validated Breast Q and National Quality of Life surveys. Divided into 3 main topics: body image, femininity and sexuality, and outside influences. Plus demographic info	Selection bias - population that is already interested in BR. No information about classification of statements into sexuality and femininity statements, body image statements and influencing factor statements. Lots of potential overlap in these categories. Contradiction between the finding that 51.6% reported their physician urged them to have BR and their conclusion that women made the decision autonomously. No questions about practical issues	Overall responses: Women agreed more strongly with body image questions than sexual function or femininity questions Top 3 sexuality/femininity reasons: Feel more sexually attractive (60%); wear more flattening clothes (49.7%); will feel less feminine if DON'T have BR (49%) Top 3 body image reasons: Maintain balanced appearance (76.7%); positive effect on body image (63.9%); more satisfied with the way my body looks (63.2%) Primary motivations: were to maintain balanced appearance (76%); to continue to feel feminine (34%); and to maintain sexual functioning (7.7%). 20 statements on sexuality and femininity; 10 on body image and 10 on influencing factors - see Tables 2 and 3 and 5	No significant diff's between sexuality/ femininity statements and body image statements based on demographic features. Women pursuing BR are more motivated by concerns of body image than issues of sexual- ity or femininity, which is independent of demographic characteristics. 51.6% reported physician urged them to have BR; 47% felt reputation of plastic surgeon influenced their decision; 58% discussed op with other women considering BR; Women made decision automatically - only 15.5% noted opinion of friends, family or spouse important in decision-making (contradicts influence of surgeon)	16
Elder et al. (2005) [46]	Prospective enrollment with pre-op and post-op questionnaires	Medical Outcome Study 36-item Short Form (SF-36) plus study-specific questions on expectations and satisfaction with reconstruction	None stated. Young sample. SF-36 not cancer-specific	Reasons for IBR: To avoid wearing prosthesis (91%); To feel whole again (90%); to enhance self-worth and emotional health (86%); To wear same type of clothing as before Mx (84%); To feel attractive (83%); To feel the way I did before BC (8%); To not be constantly reminded I have cancer (46%); To be more attractive to my partner (41%); To feel less self-conscious during sexual activity (36%); To improve my relationship with my partner (8%); Mainly because my partner wants me to (1%)	IBR patients experienced significant increase in QoL over the first post-op year, reaching levels comparable with the normal population. Reasons for recon both practical and emotional. Important to inform women considering IBR that results may not be ideal aesthetically, but great majority still satisfied with the outcome. Women seemed to have realistic expectations and most wanted BR for themselves rather than partners. Women very satisfied with general outcome and moderately satisfied with aesthetic outcome	21
Flitcroft et al. (2016) [37]	Largely prospective qualitative methodology	3 questionnaires, adapted from Reaby, on reasons for IBR, DBR or NBR	Homogeneity of sample; subjective allocation of statements into domains. Recall unlikely. Small n for DBR and NBR. Reasons not ranked	Top reasons: IBR: Feel good about myself (25%); Feel more balanced (23%); Wear different clothing (21%) DBR: Too young to be without permanent breast (71%); Wear different clothing (71%); Feel whole again (57%); Feel more balanced (57%); Regain femininity (57%); Feel good about myself (57%); BR essential for emotional well-being (57%) NBR: Don't want more surgery (67%); Only want to get rid of cancer (58%); Not essential for emotional well-being (58%); not essential for physical well-being (58%)	Asking about reasons can help clinicians to check women's understanding and expectations; help researchers sort out the relative role of choice versus outcomes in satisfaction with BR and help women to clarify their own decision. Surgeon's should not have primary role in decision making but discuss all BR options with all clinically eligible women	20

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Gopie et al. (2011) [47]	Mixed prospective & retrospective semi-structured interviews	Interviews covered motivational aspects of decision-making process, containing contextual factors (personal, social & clinical situation), personal views and expectations re BR	Difficult to sort out overlap between therapeutic and prophylactic Mx, timing and choice of BR; article states that "The majority of patients were aware of all BR options", but only two of six participating hospitals offered DIEP; exact proportions of women who answered reasons not given - used descriptors such as "most, around half, some"; only a few sample questions provided; responses not matched to clinical data; age provided at time of interview, not time of surgery, wide variation in time since breast cancer diagnosis: Mean 35.6 (with large SD of 74.6 months); recall bias.	Reasons for BR: Too young to live without breasts; to avoid wearing, or get rid of, external prosthesis; wishing to feel more feminine and self-confident; would not feel feminine without breasts; breasts needed to feel normal; want to be or stay 'representative' in clothing Reasons for DBR: Over half wanted to first recover from breast cancer treatment, physically and emotionally Reasons for IBR: Most not particularly concerned with timing - a few wanted to move on with life asap. Therapeutic versus Prophylactic: Unilateral therapeutic - wanted symmetry and to feel more complete; bilateral prophylactic - BR an integral part of treatment; BR associated with risk reduction and anxiety reduction; for some it was necessary or wouldn't have prophylactic Mx. Reasons for Implant: Younger, more pragmatic, wanted shorter recovery time, shorter anaesthetic, return to normal more quickly, better aesthetic outcomes - no donor scars. Some ineligible for autologous	Consistent with previous findings. Difficult to distinguish between clinical and motivational aspects of decision-making and their relative influence. Patients' motives for implant BR were primarily related to surgical issues, whereas women who chose DIEP especially focussed on regaining a similar breast to the one they lost. Clinical variables (therapeutic or prophylactic Mx, breast irradiation and waiting lists) can be of great importance in decision-making process	18
Handel et al. (1990) [22] ^b	Retrospective questionnaires	Questionnaires asked about demographic info, information about BR, attitude of primary surgeon, fear of complications, fear of increased risk of recurrence	Only 5% uninsured - selection bias; recall bias. Collected data on chemotherapy but not radiotherapy (more likely to affect BR options)	Reasons for NBR: Uncertainty about outcome (60%); possible complications from more surgery (42%); considered themselves too old (40%); concerned about increased risk of future cancer (34%) Factors associated with BR: Significantly (statistically) less likely to have BR if older, worried about complications, uncertain about outcome and fear about effect of BR on detection of recurrence	45% chose BR; 55% did not. Of this latter group, 18% still deciding. No difference in marital status, chemotherapy or knowing someone with a bad result. Influence of surgeon not significant; 83% of those who had BR, either satisfied or very satisfied. Over 94% aware of BR as an option following Mx doesn't say whether they knew about BR before their Mx/Techniques improving - surgeons should encourage BR, particularly IBR	15

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Héquet et al. (2013) [48]	Retrospective questionnaire. Analysed in two groups: NBR versus IBR + DBR	Own questionnaire distributed June 2011	Majority of analysis was done on whole cohort of 1,937 patients, but questionnaire only completed by 61 women who did not have BR. Thus the majority of the paper is about factors associated with NBR/BR. Recall bias - authors acknowledge that patients were probably responding according to how they felt at the time of the survey, several years after the decision was made, but argue that's not a limitation because DBR remains an option for several years	Reasons for NBR: 49 (80%) personal choice; 11 (18%) not offered by surgeon; 12 (19.7%) personal choice plus not offered by surgeon; 5 (8.2%) medical reasons. Personal choice covered: refusal of further surgery (59%); acceptance of body symmetry or asymmetry? (38%); risk of complications (30%); advanced age (23%); fear of masking recurrence (18%); acceptance of body asymmetry by partner (18%); financial cost (15%); post-Mx pain (6.6%)	Significantly (statistically) more likely to choose NBR if aged over 50 and had invasive cancer; if had primary invasive rather than DCIS or recurrence; radiotherapy (potentially confounded by cancer stage and timing of BR). Financial costs not significant. 62% of patients were unsatisfied with the info they received. BR free in public system but limited by the number of surgeons and operating time. Out of pocket costs for private patients. Better understanding the factors that influence NBR decision can help us adapt the information to serve the patient's personal needs	13
Keith et al. (2003) [23] ^b	Prospective; questionnaires administered before first chemo cycle	Hospital Anxiety & Depression Scale; Eysenck Personality Questionnaire (revised); BR questionnaire - ad hoc q to assess knowledge about BR, desire for BR, and attitudes and concerns about BR	No information provided about what surgery they had. Only women eligible for neoadjuvant chemo invited - does not give reason. Includes patients with WLE as well as Mx. Exact number of participants not clear. No data on how many Mx versus WLE. Between 40–56% of those wanting BR did not answer questions related to their feelings about BR. "Many had simply written 'not interested' across that part of the questionnaire". Figures in text do not always match figures in Table IV	Factors associated with BR, rather than reasons. Younger and more depressed women more likely to want BR. Of those who wanted BR: 74% wanted it at 3 months rather than 6 months; 63% were afraid BR might mask recurrence; 39% thought BR might cause recurrence; and 89% concerned with appearance post-op; 94% thought BR would be beneficial for their self-esteem; 86% thought it would give them greater freedom to wear any clothing and 84% thought the cosmetic appearance of BR better than that of a prosthesis; 78% thought it would give them greater freedom to do more everyday things; 51% thought BR helpful to woman in her physical relationship with partner; 43% thought BR helpful to her partner in their physical relationship; 22% heard too many conflicting opinions	IBR not offered. Only 57% had heard about BR. Almost 50% indicated they would like BR if possible. Neuroticism, extroversion, tough-mindedness, marital status and tumour size were not significant independent predictors of wish for BR. More IBR will limit time to consider these things. Need for consultants to discuss them, especially fears about recurrence and masking of recurrence. A better understanding of the concerns of women would allow more informed pre-operative discussion	18

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Lam et al. (2005) [21] ^b	Retrospective (short-term) questionnaire and interview?	Own questionnaire, but validated in previous study?	Info on timing and type of BR not provided. Choice influence items (reasons) not all appropriate to BR (e.g. avoiding chemo or radiotherapy), but still ranked highly by women choosing BR. Participation rate 49.3%; 207 women excluded from the analysis because “medical considerations dictated their surgical approach.” Recall bias unlikely in short time span	Reasons for choice (either BCS, Mx only or Mx + BR): 19 statements women ranked from 1 to 5 (mean scores provided). Top 9 reasons of those who chose BR (ranked): cancer is cured; cancer not return; avoid having further surgery in the future; surgery is absolutely necessary; maintain femininity; knowing doctor's preference; partner supports decision; maintain physical appearance; have confidence in surgeon. Factors associated with BR. Those choosing BR were younger. Women choosing BCS and Mx with BR placed more emphasis on appearance and body image concerns than women who chose Mx only	Survival concerns rather than physical appearance, age and lack of recommendation push Chinese women to choose MRM as BCS is, incorrectly often seen as less efficacious. Recommending BCS increases BCS choice. Surgeons recommendations very influential BCS often seen as less safe; women don't realise may need Mx + adjuvant treatment. Only 50% offered BR by surgeon and only 5% took up the offer. Women didn't understand relative treatment efficacy: “withstanding an opinion so as not to influence choice is unhelpful for the majority of these women.” Need for surgeons to assess any misconceptions or false beliefs?	21
Lardi et al. (2013) [20] ^b	Retrospective questionnaire	Own survey instrument covering knowledge about need for Mx; attitude to BR at time of Mx and during follow-up; body image shortly after Mx and when survey completed	Only women aged <70 sent questionnaires (selection bias). Stated that “during the aftercare period, only a minority of the respondents (43.8%) wished to discuss the option of BR” but this “minority” was 43.8% (close to half), so this finding does not support their conclusion	Factors associated with BR: Significantly younger; greater view of injury to body image Reasons for NBR: Comfortable the way I am (21.6%); don't want to go through another operation and hospital stay (19.2%); risks of another operation too high (16%); don't believe aesthetic results will be satisfactory (14.5%); worried about not being able to detect recurrence (10.4%); too old (10.4%); not relevant for my body image (8%)	11 did not discuss BR at diagnosis (seven didn't want information); older age and advanced disease associated with not needing to know at that time. 19 did not receive info after, even though 6 wanted to. Concludes info about BR should be offered but not compulsory as 40% of their patients didn't want info at time of surgery or later. These women should not be pushed. Women in 60's and those in 70's with excellent health, should also be offered BR as body image doesn't necessarily age. Estimates one-third view BR as essential; one-third see it as autonomous choice to live with scar - doesn't affect femininity; one-third ambivalent - need most convincing. Found no evidence that low number of patients who chose DBR is due to lack of info - the majority of patients overcome their negative attitudes to their Mx quickly and are uninterested in BR	18

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Lee et al. (2010) [32] ^c	7 focus groups and 15 semi-structured interviews	Discussed decision about BR and the decision-making process. Thematic analysis	Recall bias (up to five years since Mx). Authors did not discuss any limitations	Not reasons, but goals/concerns e.g., need to look good in clothing, want to avoid prosthesis, influence of surgeon important. No percentages provided. Participants reported on how they made their decisions about recon, their experience with recon and how they felt about their decisions	Some breast cancer patients are unprepared for the full effect of surgery – and discussions about recon should include these key concerns. Need for more info about magnitude of surgery and recovery, so women can plan, and about numbness, tingling, affect on donor site etc. Women were primarily concerned with how they look in clothing rather than naked. Even though women did not report positively on the ‘cosmetic outcome’ they were generally satisfied	15
Manne et al. (2016) [35]	Prospective questionnaires	Ottawa Decision Support Framework; 19 item knowledge survey developed by surgeon; Plus 17 item RFR and 8 item RFNR; Plus two scales on decision preparedness; plus 16 item Decisional Conflict Scale; plus State-Trait Anxiety Inventory; plus 2 questions - Have they made a decision? and What option are they most interested in?	This study was a subset of a decision aid trial and included patients considering BR but who hadn't decided between WLE & Mx - so BR not even an option for some of them. Small, homogenous, non-representative sample - too few women over 60, from minority backgrounds, and most were insured. No information on what surgery they actually had. Unsure about their rationale for excluding items due to low response rates as some excluded items had higher responses than included items - ? selection bias for questionnaire items. Different information levels - some women had seen plastic surgeons	33 reasons to choose or not choose BR— see Table 2. Percentages not given. Scores between 1 and 5 Highest ranked BR: Symmetry; wake up with breast; didn't want to see scar and no breast; feel whole again Lowest ranked BR: Related to partner and forgetting about BC NBR: Highest related to medical risks of more surgery, complications, scarring, pain Lowest NBR: Uncomfortable asking surgeon about BR. Eight questions were excluded in final survey. These included questions about knowledge of risks and benefits of BR These topics were covered by the preparation for decision scale (a/c to authors)	Almost half of the women had made a decision about BR prior to initial surgery—most chose to have BR, and most of those chose implants. Those who had not decided had significantly higher scores on reasons not to choose BR, lower levels of decisional preparedness, and greater decisional conflict, BUT not significantly different BR knowledge or scores on reasons to chose BR scale. Knowledge about BR, decisional preparedness and BR decisional conflict relatively low - decision to have BR relatively easy. Women considering BR may benefit from decisional support. Healthcare professionals may facilitate decision making by focusing on reasons for each patient's uncertainty and unaddressed concerns. Those who were unsure not necessarily less informed	20
Meretoja and Suominen (2005) [49]	Retrospective questionnaire	20 item self-constructed questionnaire, covering demographics, health, adequacy of info, satisfaction with outcome, use of prosthesis, wish for recon or other plastics ops and why/why not	Comparing BCS with Mx +/- BR. No info on which operations they had and satisfaction with BR outcomes. Assumes reasons why older women haven't had BR (fear, breasts less important, satisfied with Mx) but hasn't asked them those questions. Questions asked are not provided. Recall bias	BR (n = 12): Body image problems (75%); inconvenience of prosthesis (67%); self-esteem problems (42%); missing breast reminds of cancer (33%); doctor's recommendation (17%). NBR (n = 31): Satisfaction with status quo (65%), operation too much trouble (19%); fear of operation (16%); operation would remind of cancer (3%)	Clear trend of interest in BR declining with age, 28% of women with Mx wanted BR (83% of those under 45). Factors affecting patient's wish for BR: statistically significantly less likely if older, and had prior chemotherapy or radiotherapy. Proposes patients who have consider illness more serious and choose not to have BR	15

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Morrow et al. (2014) [26] ^b	Retrospective questionnaires × 2 time points	Own questionnaire covering: BR or not since Mx; patient satisfaction with BR decision-making process - satisfied with decision, any regret, satisfied with info on BR. Also looked at reasons why didn't have BR or DBR	Decay in longitudinal sample may have introduced selection bias (non-respondents to follow up survey more likely to be black or Latina). Limited to two metro areas - different from rural areas where plastic surgeons less available. Recall bias. Self-reported surgery. Informed consent waived because completion of the survey was believed to indicate consent. ^c ? overly complex statistical analysis	NBR: <i>Patient factors</i> avoid additional surgery (48.5%), feel BR not important (33.8%); fear of implants (36.3%), interference with future cancer detection (23.9%); concern about complications (33.6%); time off work or from family (16.1%). Systems factors not aware of BR (18.1%); trouble finding surgeon (5.6%); no insurance coverage (11.8%) or surgeon did not take insurance (7.8%). Black and Latina patients same reasons but different importance—significant ethnic/racial gradients for some of the NBR reasons DBR: Clinical patient factors: need to focus on cancer treatment (68.7%), chemo (50.7%) or RT (26.3%). Patient attitudes: Not sure wanted BR (10.1%); too much time off work or family (6.7%). Systems factors: Not aware (14.3%); problems with initial breast surgery (8.1%); no insurance (10.3%)	16.8% of Mx patients delayed BR, suggesting that most women who desire BR have access to IBR. Significantly less likely to have BR if black, no more than high school education, no private insurance, major comorbidity, older, live in LA county, had chemo. Racial and ethnic disparities evident. 13.3% dissatisfied with recon decision-making process, but dissatisfaction higher among non-whites (statistically significant for black or Latina women, but not for lower income or education). 14.3% of DBR patients were unaware of BR option at time of Mx and 18.1% of NBRs reported lack of knowledge about BR. Little residual demand for BR among women who had not had it by 4 years since diagnosis (recon rates largely reflect patient demand). Only 30 of 263 patients (11.4%) who had not undergone BR by then were still considering it. Most patients satisfied with BR decision-making process. Need for better education (e.g. re safety of BR), more input from plastics, and the use of decision tools to improve patient-level factors	18
Neill et al. (1988) [31]	Interviews (each woman at least twice). This study reports on findings from first interview	Own interview guide covering demographic items, clinical data, what treatment options discussed by whom, how they learned about BR and from whom, decision-making process, information seeking, use of resources, personal reasons for BR factors influencing choice	Percentages for reasons not provided. Mainly white and well-educated about healthcare choices. Recall bias, n = 11. Subjects who rejected BR were excluded	Reasons for BR: To avoid a prosthesis - both pragmatic issues and need for perceiving oneself as having normal body integrity. Strong focus on regaining normality, including appearance, awareness of social self, body integrity and to a lesser extent physical activity, feel whole, return to a normal life, returning to work, to put cancer experience behind them. Choice of implant because least invasive and most body-preserving procedure; choice of TRAM because avoiding foreign object and retaining body integrity	Recon minimised the negative consequences of Mx. Main theme was "Getting my life back". Despite much information seeking and talking it over, all participants were adamant in asserting that the decision for recon and its type was their decision. Information seeking and focus on learning about and making a decision on BR may be part of a coping strategy - a sense of regaining control when women need it most	14

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Nelson et al. (2013) [33]	Retrospective audit of BR and DBR, plus survey of DBR. To minimise recall bias, compared patients operated on in 2005–2007, with those operated in 2008–2009	Survey containing several study-specific tools plus Sect. 3 of Breast Q. Covered treatment decisions, recon choice, opinion of outcome, sources of info and satisfaction with pre-op counselling	Use of census data to estimate income. No data on insurance. Low response rate (40%). Responding cohort well educated, most currently employed, nearly half had household income > \$100 K.	DBR: Strongly influenced by desire to feel feminine, look natural, wear different clothes and to get life back (scored 5/5). Less influenced by need for additional surgery and by doctor's recommendations (scored 3/5) Reasons for choosing DBR: Not worried about BR at time of diagnosis (55%); doctor's recommendation (52%); wait until all treatment finished (48%), wait until after radiotherapy (38%), not offered IBR (30%), wait until I was cancer free (37%, I didn't have a plastic surgeon (20%), I didn't want BR (13%), I liked the idea of 2 operations better than one long one (13%), it would allow me to spread the costs out (5%), I didn't think I could afford BR (5%)	At time of Mx, nearly 20% reported no discussion of BR. Only 51% discussed IBR prior to electing DBR and 39% had no discussion about advantages or disadvantages of BR options. 31% did not discuss different options for DBR, DBRs tended to be from less affluent areas, may be related to less patient education. Plastic surgeons, then breast surgeons strongly influenced d-n. Satisfied with BR outcomes – 83% do it again, 87% encourage others, 75% changed life for better and 84% had no regrets. 30% did not have a choice on the timing. 45% of women would have chosen IBR instead of DBR if given the option. Women may not be receiving adequate info prior to Mx - need to improve prep patient education and educate breast oncology colleagues. NY passed law that BR discussion must occur prior to Mx - all info and all options should be discussed	19
Nozawa et al. (2015) [50]	Retrospective questionnaires. Methodology questionable as includes those planning to have BR	Own questionnaire covering satisfaction with BR, reasons for not having IBR, reasons for not having DBR, satisfaction with d-m and choice. Also General Health Questionnaire and lots of others	Includes BR for those who had BCS, but no information on what this involved. Number of participants incorrect in abstract. Only considered young women (aged 45 or younger). Included women who had planned BR, but not actually had it, in their analysis - poor methodology. Time since Mx not stated - ? recall bias. Lot of missing data. Findings do not support conclusions. 56 patients actually had BR, but BR type not mentioned. 31 subcutaneous Mx + 99 Mx = 130 Mx.	Reasons for NOT having IBR: Worried about spread, recurrence of cancer (40.7%); no more surgery (34.1%); BR too much to think about now (33.3%); unnecessary (32.5%); financial reasons (32.5%); it is an illness so nothing can be done (17.9%); would interrupt work, housework and parenting (13%); not aesthetically pleasing (10.6%); just didn't want to (6.5%); family and friends against it (0.8%) Reasons for NOT having DBR: Expensive (45.7%); cause distress to my body (40.4%); concern about foreign substance in body (39.1%); did not want additional scars (35.1%); worried about relapse (31.1%); did not have sufficient knowledge (23.8%); illness and nothing could be done (16.6%); takes too much time (14.6%); not sure who to discuss it with (11.9%); 'other reasons' (14.6%)	Dominant reasons for not having IBR: anxiety regarding relapse and physical distress, followed by psychological and economic unaffordability. Extremely rare for patient to have DBR, largely due to expense, but also to increased apprehension over time about having more surgery. Around 25% of Mx patients did not receive any info or explanation about BR, or did not fully understand the info they received. Conclude that their hypotheses were supported, i.e. BR group are likely to experience less physical changes, to evaluate themselves as attractive, to be more active and to be satisfied with decision-making. Concluded that regardless of deciding to undergo BR or not, cognitive interventions are needed to avoid "fixed self-consciousness and concerns over treated areas of the body"	11

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Panieri et al. (2003) [51]	Prospective audit	Prospective record of the patients' demographic data, whether recon was offered or not, and the reasons for the decision.	No information is provided on age, yet they claim that the decision to accept or decline BR is unrelated to age. No info on type of BR ('most had TRAMS'). The most popular reason for refusing IBR, 'prefer simpler procedure', is inferred to reflect 'patients' anxiety and fear of unknown complications, delays and possible further procedures'. Selection bias: 52 not offered BR because of combinations of cosmetic considerations (morbidity, ptotic breasts, or suitable for BCS (31 cases); significant comorbidity (25 cases); advanced age (13 cases); and oncological factors (large tumours or expected to require PMRT (9 cases)	Patient-reported reasons to decline BR: Prefer simpler procedure (66%); breast appearance not considered important (29%); preferred BCS (10%), did not have a partner (6%), felt they were too old (4%) or had religious reasons (4%)	135 (76%) of women were judged suitable for locoregional surgery. BR only offered to 83 patients (61% of 135). 51 of these 83 (61%) declined BR. Practical considerations reduced the number of suitable patients for IBR (from "the majority" of patients to "approximately 60%"). These practical (non-patient-reported) considerations included: extensive use of Mx + BR puts pressure on theatre lists; differences of opinion – plastics preferred Mx + BR; surgical and medical oncologists preferred BCS. In the absence of good prospective studies comparing the two, final decision is subjective and is dictated by local expertise, ongoing audit of surgical results, length of surgical waiting lists and availability of post-op RT. Pensioners and widows least likely to accept recon, but not statistically significant; BR not related to age; race, employment or marital status. Concludes "many" patients suitable for recon, but < half accepted it	11
Reaby (1998) [34]	Retrospective questionnaire and semi-structured telephone interviews	Questionnaire covered demographic info, no of years since Mx, unilateral or bilateral, chemo, RT, post-Mx chances of cure, if given info on BR before Mx, whether this info lessened trauma of Mx and satisfaction with either prosthesis or BR. Interview questions covered, reasons for choice & difficulty of decision	Recall bias. Low participation rate. Limitations not discussed	NBR major reasons: Fear of complications (25%); too old (22%); not given the option (12%); did not want additional surgery (11%); unnatural (8%); not needed for physical & emotional well-being (8%); too painful (6%); only wanted to get rid of cancer (6%); too expensive (2%) BR major reasons: To feel whole again (51%); to be rid of external prosthesis (29%); help forget about being a cancer victim (10%); surgeon strongly recommended (10%)	Age difference significant – younger more likely to have BR. No difference in satisfaction with outcome between the 2 groups. 87% of NBR did not find decision hard (main reason was they were too old or lived alone so no point). 100% of BR group did not find the decision hard. Women need to be informed and educated to prevent unnecessary fear. Women generally chose BR because of a personal sense that their femininity and body image would be damaged by Mx. 45 (70%) of NBR group given info re BR prior to Mx. 17 (27%) of NBR group did not receive info on BR either before or after Mx. 12% of NBR not given the option. Knowing about BR lessened the negative impact of Mx in over one-third of the recon group	16

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Rowland et al. (1993) [52] ^c	Prospective assessment of women who had Mx plus post-operative interview a minimum of 2 months following BR	Surgical and psychological measures (consultation, interview and self-reported questionnaire)	Study conducted at a time when Mx was main treatment and BCS not widely available. Women had to overcome stigma of asking for BR. Only DBR offered at that time. Recall bias. Drop-out bias not a major source of bias (according to them)	Expectations rather than reasons. 16 statements starting with "Reconstructive surgery will ... improve family relations (22%); improve work situation (24%); improve social relations (30%); less worry about health (47%); improve dating or relations with husband (59%); improve sexual relations (73%); make me less conscious of having BC (71%); make life easier generally (83%); improve physical comfort (88%); hide Mx (83%); make me more self-confident (88%); make me feel more attractive (95%); make me look better (95%); make me feel more like a normal woman (89%); simplify shopping for clothes (92%); allow me to wear clothes more freely (99%). Most frequent reasons for seeking BR: to be rid of prosthesis; to 'feel whole again'; to restore symmetry and decrease self-consciousness about appearance. Women sought surgery for themselves; 60% said partner neutral or even opposed to BR	Most women felt surgery had met or exceeded expectations. Women's expectations of physical & psych benefits of recon rated as realistic - surgery was expected to improve aspects of daily life and to have least impact on personal relations. Results dispelled myths that women seeking recon were neurotic or even psychotic. Attractiveness not just an issue for younger women. With few exceptions, net effect increased both observed and stated satisfaction with psychosocial and sexual function. Women sought surgery for themselves – 60% of women said partner was neutral or even opposed to BR. Surprising findings of drop in self-esteem post BR and less worried about their health. Findings highlight overwhelmingly positive effects of BR	22
Schain et al. (1985) [53]	Retrospective questionnaires	Brief Symptom Inventory (a standardised psychological symptom inventory) and detailed questionnaire developed by authors	Data on RFR only added halfway through data collection, so number of patient numbers with this specific data is approximately half of those for rest of variables (n = 29). Retrospective self-reports of women with a variable period of time between Mx, BR and psych testing. Recall bias; small n with reasons	Reasons for seeking BR (varied according to timing): Able to wear more types of clothes (79%); to get rid of external prosthesis (79%); to feel more balanced (72%); to feel 'whole again' (72%); to less preoccupied with my physical state (72%); to feel more feminine (66%); to become less preoccupied with my cancer (59%); to improve my sexual relations (31%); to improve my marital relations (17%)	IBR patients and those who had BR within 12 months had significantly less recalled distress (less overall trauma and intensity of pain) about their Mx than those who had it later. Radiotherapy and chemotherapy did not appear to make patients delay recon. Women who delay BR experience have a greater number and severity of negative psych reactions. Early delayed group (< 12 months) showed more psych symptoms than IBR or DBR groups - not clear why. IBR may be best for certain subsets of breast cancer patients	19

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Shameem et al. (2008) [29]	Retrospective interviews	Collected info on demographic and clinical factors, whether they were aware of BR prior to surgery, whether they had been offered BR at initial consultation, reasons for choosing or not choosing BR; would they have been interested if it was an option, satisfaction with outcomes	Type of BR not mentioned. DBR not mentioned. Only significant difference, according to Table 1, was BR group more likely to be married. But the discussion states that "younger age and being married seems to be the only significant factors", although no statistical analysis of age was presented (mean age in BR group was 10.1 years younger). With IBR → 43.5% chose to improve marital relations as a reason, so not 'low on list' as author states. Malaysian guidelines cited as possible explanation for high rate of NBR, but the guidelines do recommend BR for women under 55. Conclusions often do not support data. Recall and ? selection bias	Reasons for BR: To feel whole again (95.7%); to regain femininity (91.3%); to feel more balanced (91.3%); no clothing limitation (87%); to forget about disease (52.2%); to avoid external prosthesis (43.5%); improve marital relations (43.5%); surgeon strongly recommended it (34.8%); improve sexual relations (0%) Reasons for NBR: Fear of additional surgery (68.1%); fear of surgical complications (47.8%); not essential for physical/emotional well-being (45.1%); consider self too old (43.4%); concern about future cancer (41.6%); uncertainty about outcome (33.6%); surgeon against recon (33.6%); fear of anaesthesia (28.3%); not impressed with recon seen (25.7%); lack of info on recon (9.7%); need for adjuvant therapy (8.8%); too expensive (4.4%); feels unnatural (3.5%); partner not supportive (2.8%); need to travel too far (?1.4% - reported as % in Table 2); too many work/family commitments (0%)	In this "dedicated breast surgery unit", only third of women with Mx were offered IBR. Only reported significant difference was BR group more likely to be married, but infers age also significant (mean age in BR group was 10.1 years younger, but no p values presented). Only 36.8% of those interviewed had been offered BR. 45.5% unaware of BR option. In NBR group: only 21.2% had been offered BR; of those not offered BR, 16.8% said they would have been interested. IBR: 87% satisfaction rate c.f. 79.6% in NBR group, but not statistically significant. Three autologous recon patients unhappy and regretted procedure. Malaysian clin practice guidelines state indications for BC are: age < 55, DCIS, LCIS, stage I & 2, & prophylactic Mx. Concludes major barriers in public hospitals in most Asian countries are limited operating time, low BR awareness and inadequate availability of plastic surgery services	13

Table 1 (continued)

Author (year) [Ref.]	Design/methods	Tools used	Limitations/bias*	Reasons	Conclusions	Consensus quality score (out of 24)
Somogyi et al. (2015) [54]	Online survey	Covered socio-demographic and clinical data, patients' experience with BC, timing of awareness of BR options, info sources, influential individuals and reasons for choosing BR or not	Only considered social and emotional reasons - not practical and other reasons. Seven items framed in the present tense, reflecting when they made the decision). Some odd reasons for choosing BR e.g. "Not looking for breast enhancement." No differentiation between BR and DBR reasons (should have been analysed separately e.g. prosthesis statement not relevant for (BR)). Selection bias: over-representation of women with specific interest in BR (members of BCNA Review & Survey Group). Recall bias. Complicated, unclear and potentially misleading methods. Did not collect information on tumour status or other comorbidities although "clinical history factors" were necessary to support their main conclusion	NBR: 14 reasons. Don't want more surgery (68.4%); don't feel the need (57.9%); Don't want recovery/rehab (54.7%); potential complications/side-effects (48.4%); don't want implants (42.1%); don't want tissue transplant surgery (34.7%); won't be satisfied with outcome (24.2%); can't afford it (20%); don't want more surgeons/doctors visits (15.8%); insufficient support at home for recovery (10.5%); too much responsibility at home (8.4%); live to far away for follow-up (5.3%); can't take time off work (4.2%); insufficient support at home while I'm in hospital (4.2%) BR: 7 social and emotional reasons for having BR. Look and feel normal as possible (93.9%); recon a step in overall recovery from cancer (88.3%); recon has helped my body image (86.4%); don't want to be reminded everyday about BC (76.4%); happy enough if look good in clothes (71.8%); prosthetics are annoying (& potentially embarrassing (67.6%); not looking for breast enhancement (57.9%)	91% recall discussing BR. Only 61% had initial discussion prior to surgery. Surgeons (plastic, then breast) most influential in d-n. Odds of having recon decrease by 3% for every year of increasing age; decrease by 28% for every point of increasing responsibility (home/work responsibility and home support); increase by 27% for every point of influence the patient rates the plastic/recon surgeon. Statistically significant differences between women offered BR and those not offered BR: women offered BR were younger (mean age 49 compared with 53); had Mx in an urban hospital and had children living at home. Concluded "A model using factors easily obtained on clinical history can be used to understand likelihood of recon." (but no information provided on clinical history). This knowledge may help identify barriers to BR, ultimately improving clinician's ability to appropriately educate Mx patients and ensure effective decision-making around BR	16
Zielinski (2014) [55]	Retrospective questionnaire	Questionnaire covered demographic info, age, urbanisation of place of residence, no of years since Mx, education, professional activity, civil state & belonging to community of post-Mx women, feeling unattractive, feeling supported and accepted from partner and next of kin, limitations of Mx on personal or professional life, knowledge of BR options. Asked to include all and choose most important	Unknown amounts of missing data; overlap between all reasons and singular reasons. Figures seem to change in different parts of the paper e.g. is it 15% or 12% who were not informed about BR?	Reasons for NBR: Usually mentioned more than one. Most important ones: Acceptance of appearance (8.2%); BR have negative influence on cancer treatment, afraid of another operation, not most important for physical condition (5.5%); too old (4.1%); fear of post-op pain, fear of unsuccessful result, doctor said there were contraindications (2.7%) Most common reasons: Age (52%); fear of another op (38.3%); fear of post-op pain (31.5%); not most important for mental state (35.6%); totally accepted appearance (30.1%); did not accept appearance, but not most important physical condition (17.8%); fear of unsuccessful recon (24.6%); negative impact on cancer treatment (27.4%); no info on possibility of BR (15%); no knowledge of BR methods (17.8%)	Most women who choose NBR have several reasons for doing so. "Most important reasons": fear of undergoing a second surgical procedure and pain related to it. An "important factor" is age. (These are actually the most common reasons, but not the most important ones)	11

^aValue placed on particular factors/influences on BR choice^bDeterminants of choice (factors associated with a particular choice)^cGoals, motivations, concerns or expectations relating to BR[†]Reasons only given for NBR

Table 2 Clinical information

Author (year) [Ref.]	Type/stage of cancer	Population demographics (age, education, SES)	Time since surgery	PMRT – Y/N	Chemotherapy	Type of surgery	Timing of recon—IBR, DBR, NBR	Type of recon (implant, autologous)
Adachi et al. (2007) [24] ^a	Stage 0–Stage IV	28–75 age (average 53); 78.4% married; 32.3% work- ing PT or F/T	average 1.4 years since “surgical treatment” (SD = 0.9)	Not stated	Not stated	67 BCS, 25 Mx only, 11 SSM & IBR	IBR	Not stated
Alderman et al. (2011) [40]	DCIS-Stage 3	Aged 79 years or younger. Mean age total: 62.4 years; mean age IBR 56.8; DBR 57.5; NBR 67.4	5–6 years post-Mx	20%	30.10%	Mx	138 (35.9%) IBR; 44 (11.5%) DBR; 202 (52.6%) NBR	Not stated
Ananian et al. (2004) [19] ^b	Not stated	average age 53.9; 71.8% part- nered; 50.85% worked; 43% above high school education	N/A (prospec- tive)	Not stated	Not stated	34 Mx (19%); 147 BR (81%)	IBR (83%); DBR (17%)	Surgeon decided specific tech- nique, considering morphological and clinical characteris- tics & possibility of PMRT. Type of BR not stated
BCNA (2011) [42] [†]	470 had ‘early breast cancer’; 12 women no diagnosis.	Under 30–80. Median age group 50–59. All states, with most responses from Vic and NSW	Not stated	Not stated	BR: 341 (71%) had BR. 67 (20%) in public and 274 (80%) in private system. NBR: 140 (29%). Of these, 36 (26%) still consid- ering options and 18 (13%) currently on a waiting list	Not stated; 55 (82%) within 6–12 months of being placed on public hospital waiting list; 8 within 1–2 years; 1 within 3–4 years. No woman longer than 4 years in public system	IBR (n = 12); DBR (n = 9)	TRAM, DIEP, STEP, SGAP
Begum et al. (2011) [25]	69 responded prophylactic (? Some had one breast diagnosis and prophylactic Mx of other breast)	age 38–61 (average 48); 57% married; 14% divorced; 29% single; 85% worked; 6% had education of degree level or higher; 13 Caucasian, 6 black African, 1 black Caribbean, 1 white Portuguese	4–35 months (mean 12.5 months) since auto- logous BR	Not stated	Not stated	Autologous	IBR (n = 12); DBR (n = 9)	TRAM, DIEP, STEP, SGAP
Clifford (1979) [43] ^c	Not stated	30–71. Mean age 46. 75% employed; 80% married	2 weeks–31 years since Mx (average 5.4 years)	Not stated	Not stated	Mx	4 IBR, 61 DBR	Implant

Table 2 (continued)

Author (year) [Ref.]	Type/stage of cancer	Population demographics (age, education, SES)	Time since surgery	PMRT – Y/N	Chemotherapy	Type of surgery	Timing of recon—IBR, DBR, NBR	Type of recon (implant, autologous)
Contant et al. (2000) [44] ^c	57 breast can- cer, 18 exten- sive DCIS, 9 prophylactic	26–64 (mean 41.5)	Questionnaire a minimum of one year after Mx and IBR. No max period provided	Not stated	Not stated	Mx	IBR	Implant
Duggal et al. (2013) [45]	Not stated	1.7% aged 20–30; 15.6% aged 30–40; 37.4% aged 40–50; 24.6% aged 50–60; 19.6% aged 60–70; 1.1% aged 70–80. 78.6% with PHII	N/A (Prospective)	Not stated	Not stated	Not stated (all sched- uled for Mx and elected to undergo plastic BR)	Not stated	Not stated
Elder et al. (2005) [46]	17 Cancer in situ, 26 T1, 28 T2, 2 T3, 3 undetermined	25–71 (median 46)	Pre-op plus 12 months post-op	22 (29%)	13 (17%) neo-adjuvant ; 29 (38%)	Mx	IBR	Implant
Flitcroft et al. (2016) [37]	Locally advanced Grade I–III	Overall age: 39–79; median age IBR: 48; median age DBR: 53; median age NBR: 64. cohabiting: 70.6%; private health insurance: 45%	N/A (prospec- tive)	Not stated YES—all	All had Mx, with or without BR post-op	32 IBR; 7 DBR; 12 NBR	27 2-stage implants; 4 direct to implant; 1 LD flap; 1 TRAM (delayed)	15 implants + 16 DBR, DIEP: 3 IBR and 13 DBR
Gopie et al. (2011) [47]	Not stated	Age at time of interview, not surgery. Implant mean age: 44.2; DIEP mean age 48.5. More detail in Table 1	Pre and post- Mx; time since Mx not stated. Mean time since BC diag- nosis given	Not stated	Not stated	15 Implants + 16 DIEPs; implants –4 unilateral and 0 bilateral cancers; 10 prophylactic mx (PM) and 5 contralateral PM and 6 bilateral PM. DIEPs – 12 unilat- eral and 1 bilateral cancers; 6 PM with 0 CPM and 3 bilateral PM	Implant: 12 IBR and 3 DBR, DIEP: 3 IBR and 13 DBR	15 implants + 16 DBR, DIEP: 3 IBR and 13 DBR
Handel et al. (1990) [22] ^b	Not stated	Relatively homogenous. NBR mean age 59 (SD 12.5); BR mean age 43 (SD 10.8)	1–9 years post-Mx	Not stated	Around 1/3	Mx only versus Mx with recon	Not stated	Not stated

Table 2 (continued)

Author (year) [Ref.]	Type/stage of cancer	Population demographics (age, education, SES)	Time since surgery	PMRT – Y/N	Chemotherapy	Type of surgery	Timing of recon—IBR, DBR, NBR	Type of recon (implant, autologous)
Héquet et al. (2013) [48]	DCIS, SBR I–III, Invasive SBR unknown	Median age 56 (range 23–97). 82.7% with IC. NBR in situ cancer 34.6%; NBR in IC 74.9%. See Table 2 for details	4–7 years post-Mx	50.2% of total cohort (1,937); 60% of all NBR (1,200)	59% of all NBR (1,200)	N/A (NBR)	N/A (NBR)	
Keith et al. (2003) [23] ^b	Newly diagnosed, large (3 cm or bigger) or locally advanced (T ₃ , T ₄ , T _x N2)	Want BR: Mean 47 (range 28–67); 85.5% partnered. Don't want BR: Mean 55 (range 37–75); 79.2% partnered	N/A (prospective)	"RT considered after surgery" - no numbers provided	100% NAC	MX versus WLE	DBR only	Not stated
Lam et al. (2005) [21] ^b	Early'; Stage 0–III	Whole cohort; mean age 52; SD 10.8	Mean 2.43 days (SD 1.66); Max 12 days following "breast surgery"	Not stated	BCS versus Mx only	Not stated (=? IBR)	Not stated (=? Implants)	
Lardi et al. (2013) [20] ^b	Early stage (stages I–III)	Age at diagnosis (31–68), median 49. Age at survey (37–70), median 56	Max b/w 1998–2009. Date questionnaire administered not provided	46	68	75—Mx only; 26 had DBR (IBR previously excluded)	DBR only = 14; DBR plus implants = 2; LD only = 2; LD plus implants = 1; Implants only = 7	DBR only = 14; DBR plus implants = 2; LD only = 2; LD plus implants = 1; Implants only = 7
Lee et al. (2010) [32] ^c	Early' stage	Age not stated. Specific focus groups held for women with lower education, from rural areas, and who were Hispanic and black	Max in last 5 years	Not stated	Not stated	Not stated	Not stated	Not stated
Manne et al. (2016) [35]	Early stage (DCIS-Stage 3a)	Mean age 50 (SD 10.5). Majority white, well-educated, <50, partnered, insured, and had not seen plastic surgeon re BR	N/A (prospective)	Not stated	Not stated	22 women chose some kind of BR	11 chose implant; 9 chose autologous	
Meretoja and Suominen (2005) [49]	Patients with distant metastases (apart from lymph nodes) excluded	Want BR: mean 49 (range 31–63). Don't want: mean 63 (44–90)	1–2 years since Mx or BCS	Want BR: 25%; did not want BR: 61%	Want BR: 42%; did not want BR: 74%	Max = 43; BCS = 41. Of 43 Mx, 12 wanted BR and 31 did not	DBR only	Not stated

Table 2 (continued)

Author (year) [Ref.]	Type/stage of cancer	Population demographics (age, education, SES)	Time since surgery	PMRT – Y/N	Chemotherapy	Type of surgery	Timing of recon—IBR, DBR, NBR	Type of recon (implant, autologous)
Morrow et al. (2014) [26] ^b	DCIS—Stage III	Age of screening sample 20–79. Mean age of actual sample 55.8 years	Time since diagnosis, not surgery: Initial survey, mean 9 months (range 5–14 months); follow-up survey, mean 50 months (range 36–65 months)	33%	65%	263 had Mx only. 222 (41.6%) had BR	146 (24.8%) IBR; 76 (16.8%) DBR	61.9% implant
Neill et al. (1988) [31]	Not stated	Mean age 48 (range 39–61)	Post BR. Time not stated	Not stated	TRAM, saline implants, silicone implants	10 IBR; 1 DBR (for medical reasons - wanted IBR)	6 TRAMs; 4 saline; 1 silicone	
Nelson et al. (2013) [33]	Stage 0–IV	Whole cohort: IBR mean age 49.7 (SD 9.3); DBR mean age 50.2 (SD 8.8)	6 months–5 years since autologous BR	DBR: pre- recon 63.9%; IBR: pre- recon 19.8%	DBR: pre-recon 78.1%; IBR: pre-recon 19.8%	autologous only	IBR + DBR	Whole cohort (n = 709). IBR = 540 (76%); DBR = 169 (24%)
Nozawa et al. (2015) [50]	DCIS - Stage IV (95 of 358 unknown)	Deliberately less than 46. Mean age 39.5 (range 27–45)	Cohort includes women with no BR, with BR completed and with BR planned. Time since Mx not stated	Not stated	53.90%	174 BCS; 101 Mx, 31 sub-cutaneous Mx, 3 none, 49 unreported. 36.7% BR rate in those with Mx. 56 already had BR - gives different BR rate of 43%	52 (92.9%) IBR; 4 (7.1%) DBR	Not stated
Panieri et al. (2003) [51]	Breast carci- noma'	Only 24% had completed high school (whole sample). Of those who chose IBR, 44% had completed high school. No info provided on age. Presumably low SES? “a rela- tively unsophisticated group of patients.”	N/A (prospec- tive)	Not stated	Not stated	69 (51%) had Mx only; 34 (25%) had BCS; 32 (24%) had Mx and IBR	All IBR	Not stated—TRAM was the most com- mon method

Table 2 (continued)

Author (year) [Ref.]	Type/stage of cancer	Population demographics (age, education, SES)	Time since surgery	PMRT – Y/N	Chemotherapy	Type of surgery	Timing of recon—IBR, DBR, NBR	Type of recon (implant, autologous)
Reaby (1998) [34]	Not stated	NBR; mean age 63; SD = 10.67; BR; mean age = 49.5; SD = 8.76	Mean time since Mx: BR, 3.0 years; NBR, 3.4 years	14%	28%	64 NBR; 31 BR	27 IBR; 4 DBR (3 within 6 months and 1 within 12 months)	All implants
Rowland et al. (1993) [52] ^c	Stage I or II	Aged 32–64 (median = 42.8)	3 months–20 years (aver- age 32.7 months) since Mx. At time of re- evaluation, ranged from 2 to 27.6 months (mean 10.8 months, SD 6.4 months)	23% had adju- vant RT OR chemo	23% had adju- vant RT OR chemo	67 had modified radi- cal Mx	All delayed (IBR rarely offered back then)	All implants
Schain et al. (1985) [53]	Not stated	Mean age 48, 13 (21%) younger than 40, 20 (31%) were 40–49; 24 (38%) 50–59; 6 (10%) 60 or older. 95% white; highly educated and mostly professional	31 (49.3%) less than 1 year since BR.	4 (6.3%)	15 (23.8%)	Slightly more than 90% had modified radical Mx	25 immediate (39.7%); 13 early (20.6%); 25 delayed (39.7%)	All implants
Shameem et al. (2008) [29]	Stage 0–III	Mean age: IBR: 41.6 years, NBR: 51.7 years	not stated	IBR: 52.2% NBR: 53.1%	IBR: 82.6% NBR: 70.8%	Mx only versus Mx with IBR	IBR: 23 NBR: 113	? Majority were implants, but 3 women complained of ongoing donor site pain, so must be autologous

Table 2 (continued)

Author (year) [Ref.]	Type/stage of cancer	Population demographics (age, education, SES)	Time since surgery	PMRT – Y/N	Chemotherapy	Type of surgery	Timing of recon—IBR, DBR, NBR	Type of recon (implant, autologous)
Somogyi et al. (2015) [54]	Not stated	Average age (whole cohort): 48.9 (SD 9.1 years). Average age for those having BR: 47.7 (SD 9.0). 35/1 (70.1%) had 'access to PHI'	not stated	Not stated	309 had BR (61.5%); 95 chose NBR	Only available for 293 Mx patients: 130 (44.4%) IBR; 163 (55.6%) DBR	140 (45%) implant; 135 (44%) autolo- gous; 34 (11%) both	
Zielinski (2014) [55]	Malignancy	Aged 37–79 (mean 58). 34 in their 60 s	1–26 years since Mx	Not Stated	Not stated	Mx only	N/A (NBR)	N/A (NBR)

BCS breast conserving surgery, IC invasive cancer, DCIS ductal carcinoma in situ, Mx mastectomy, SD standard deviation

^aValue placed on particular factors/influences on BR choice

^bDeterminants of choice (factors associated with a particular choice)

^cGoals, motivations, concerns or expectations relating to BR

^dReasons only given for NBR

and one each from Hong Kong, Switzerland, Sweden, Finland, South Africa, Malaysia and Poland. Studies were conducted between the late 1970s and the end of 2014. The number of participants totalled 4269, ranging from 11 to 501 per study. There was a large gap in time between mastectomy and survey/interview, which ranged from 2 weeks to 31 years. The quality score ranged from 11 to 22 out of a possible 24.

The majority of studies (67%) used retrospective methods: 13 employed retrospective questionnaires only [20, 22, 24, 33, 40, 42, 48–50, 53–55]; five used retrospective interviews only [25, 29, 31, 32, 43]; and two used a combination of retrospective questionnaires and interviews [21, 34]. Four studies used prospective questionnaires [19, 23, 35, 45] and one a prospective patient audit [51]. Five studies employed both prospective and retrospective assessments, three of these using questionnaires [37, 44, 46], one interviews [47] and one questionnaires and interviews [52].

Clinical and demographic information

Table 2 provides information on the stage of cancer, mean age and age range, other demographic information provided, time since mastectomy and BR, adjuvant breast cancer treatments and the type and timing of surgery. The type/stage of cancer was not stated in 12 of the studies [19, 22, 25, 31, 34, 43, 45, 47, 51, 53–55]. Where specified, cancer stage/type ranged from stage 0 (ductal carcinoma in situ) to stage IV (metastatic breast cancer).

Age data were difficult to compare across studies. Overall, the reported mean age ranged from 39.5 to 58 years (for IBR and DBR) and from 51.7 to 67 years (for NBR). Age was not stated at all in two studies [32, 51]; median age was given in five studies [20, 37, 46, 48, 52] and median age range in two studies [42, 45]. Other studies used the mean age. Where more than one group was examined (22 studies) age by BR group (IBR, DB, NBR) was only specified in eight studies [22, 23, 29, 33, 34, 37, 40, 54].

Reasons for BR by domains

Table 3 provides a summary of the patient-reported reasons for choice of IBR, DBR and NBR, as discussed in the 30 publications included in this review, and categorised within their relevant domains. This content analysis approach, whereby the 103 identified reasons were categorised into eight previously determined domains, or groupings of similar reasons, allows further analysis as to the relevant contribution of each major group of reasons within the literature. Table 4 illustrates the proportion of appropriate studies each domain was relevant to. The main patient-reported reasons for wanting BR—either immediate or delayed—relate to the desire of women to feel and look 'normal'

(70% of publications) or ‘good’ (85% of publications). Being practical (83%) was a major determinant of choice for all women, even those who chose to not have BR, while the influence of others was less commonly cited (60% of publications). Fifty-two percent of publications cited relationship expectations as relevant for choice of IBR or DBR, while fear was influential in either delaying or declining BR in the vast majority of studies (91%). Reasons for choice of immediate versus delayed BR were provided in 57% of studies, and the majority of studies (80%) of women’s reasons for declining BR cited BR as being unnecessary.

BR techniques have improved over the years, increasing the range of BR options for women, as well as the possibility of having BR either as an immediate or delayed procedure. However, the reasons for wanting to have BR have generally not changed. The oldest study in this review, published in the US in 1979, identified women’s motivations for undergoing BR [42]. These motivations fitted very neatly into the domains formed to categorise women’s reasons for choosing either IBR or DBR in 2016 [37], as did the reasons provided by women in all studies included in this review. Our findings indicate that women’s reasons for wanting or not wanting BR are similar across time, cultural backgrounds and health system settings. They also suggest the domains used are appropriate and comprehensive, as Table 4 demonstrates.

Thematic analysis

This comprehensive review identified three recurrent themes across studies.

Lack of information about BR options

Lack of information was a common theme. In some studies, women were not aware of the full range of BR options. In other studies, there were participants who remained unaware that BR even existed [5, 43]. Eighty percent of studies included in this review commented on the lack of information women had about BR options. For example, one study reported only 57% of participants had heard about BR [23], another stated 45.5% were unaware of BR as an option [29], and another noted 18% of NBR participants were not aware of BR [40]. A study of Japanese women [50] reported around 25% of mastectomy patients did not receive any information or explanation about BR, or did not fully understand the information they received. The study by Nelson [33] found almost 20% of participants reported no discussion of BR prior to mastectomy, 41% had no discussion about the advantages and disadvantages of different BR options and 49% had not discussed the option of IBR prior to choosing DBR.

Lack of genuine choice

A second major finding is the lack of genuine choice women have been offered when making the difficult decision to have or not have BR. Only one study offered all women all BR options [37], while three studies only provided reasons for women choosing to not have BR [42, 48, 55]. It was possible to clearly identify a lack of choice in BR options in 13 of the remaining 26 studies (50%) that cited reasons for BR [19, 21, 23, 25, 26, 29, 33, 34, 44, 47, 50, 51, 54] but this rate is likely to be higher, given complete information about the type and/or timing of BR offered was not reported in half the studies.

Reasons for this lack of choice include either the surgeon not offering BR, or only offering a specific type of BR. In one study, 207 of 405 women who agreed to participate (51%) were excluded from the analysis because “medical considerations dictated their surgical approach” [21]. A South African study reported 52 out of 135 women (38.5%), previously judged suitable for locoregional surgery, were not offered BR because of combinations of factors including morbid obesity, ptotic breasts, significant comorbidity, advanced age and expected post-mastectomy radiotherapy [PMRT] [51].

In some studies, women were able to choose BR, but not the type or timing of reconstruction. For example, participants in the Ananian study [19] were given a choice of BR or no BR. However, if they opted for BR, the surgeon decided what type of BR they would have [19]. Similarly, women in the Contant study [44] were given an information module and in a follow-up consultation within two weeks, the “recommended surgical treatment” (implant-based IBR) was discussed [44]. Thirty percent of DBR patients in another study had not been given any choice about the timing, despite almost half of them (45%) stating post-operatively that they would have chosen IBR if given the option [33].

Shameem’s study also highlighted the role of the surgeon, with 33.6% of NBR participants stating their surgeon was against reconstruction, close to the same proportion that were offered BR (36.8%) [29]. Hequé found that the surgeon not offering BR was the main reason for NBR in 18% of cases and a contributing reason in a further 20% [48]. A low-quality study concluded that lack of information was not an important factor in decision-making, although 15% of women identified it as a reason, and 10% as the reason for not undergoing BR [55].

Health system limitations

Finally, the review identified a range of health system factors that may also limit a woman’s access to BR, such as cost (hospital, surgery, implants, time off work) [29, 50].

Even in France and Australia, where BR is available free of charge in the public system, cost was noted as an important issue for not pursuing BR [37, 42, 48]. In these countries, women face a trade-off between decreased hospital costs and increased waiting times [42, 48] and the cost of time off work is also a consideration.

Lack of insurance coverage [26], non-availability of BR in their local area [42], restrictive national clinical guidelines [29], and shortage of operating time and hospital facilities [25, 29, 51] have also been cited as health system barriers to BR.

Discussion

Quality of included studies

Half of the studies ($n=15$) scored 18 or more (75%) in their quality assessment. The heterogeneity of studies in this systematic review precluded any detailed analysis by type, timing or setting of BR. The majority of studies (67%) were retrospective, with the potential for recall bias increasing the longer the time since mastectomy. However, a prospective methodology did not automatically equate to a higher quality score, nor did a combination of questionnaire and interview methods.

One-third of included articles did not have reasons for choice as their primary outcome ($n=10$) and the earlier studies were written at a time when only delayed implant-based BR was locally available (pre-2006; $n=9$). However, many were also high quality, large studies, where all BR options were technically available, even if all options were not offered to all clinically eligible participants.

Appropriateness of domains

The categorisation of 103 reasons discussed in the 30 articles into eight domains appears to be a valid means of analysing a great range of data. We acknowledge the use of domains we have previously created to categorise reasons for choice of BR in this study leaves us open to criticisms of selection bias. To negate this criticism, we have been transparent in our allocation of reasons to each domain (Table 3). Every reason cited in the 30 papers has been included, although the exact wording may vary, as many of the same reasons were referred to in several publications.

Policy and practice implications

This systematic review of women's reasons for the choice of IBR, DBR or NBR has provided an insight into the range of issues that women value when making this major decision at a difficult time in their lives. Several studies

have suggested that up to 50% of women undergoing mastectomy for breast cancer would choose to have BR if it was available [13, 23, 56], indicating that there is a large unmet demand for BR services. The potential benefits of BR are well known [2–9] and its value has been recognised in clinical recommendations in Australia [57], the USA [58] and the UK [59].

However, failure of practice to keep up with long-existing policy recommendations was highlighted in 2016 when Cancer Australia, the peak Australian Government body responsible for providing national leadership in cancer services, published a document entitled Influencing best practice in breast cancer [60]. Part of this document stated that it is “not appropriate to perform a mastectomy without first discussing with the patient the options of immediate or delayed breast reconstruction” [60]. Such a statement would not have been necessary if guidelines were being followed.

Failure to address barriers to genuine choice in medically suitable women who wish to have BR has equity implications. Offering all clinically eligible women a genuine choice of BR options resulted, in one metropolitan practice in Sydney, in a rate of BR uptake of 41%, without any corresponding increase in adverse outcomes [61]. This figure is a marked increase compared with previous estimates of the national Australian BR rate (9% [62], 12% [63] and 16% [18]).

Research has identified significant geographical, racial, age and socioeconomic variation in uptake of BR within Australia that cannot be explained by women's preferences for BR [14–18]. Similar variations have been documented in the UK [2] and the USA [26]. The provision of BR services requires careful planning and a ‘big picture’ view in order to avoid unintended consequences. For example, a policy of minimum volume thresholds, aimed at improving cancer care in France, has led to IBR being largely limited to specific cancer centres and regional teaching hospitals, raising concerns about geographical equity of access to BR [64].

In this review, many women were not provided with information about breast reconstruction, and information was not always presented in a manner that women could understand. It is unclear whether this was the result of omission of information by the surgeon or whether women did not recall a discussion that occurred. In 1998, Reaby [34] reported that 12% of her Australian participants who underwent mastectomy between 1986 and 1992 were not aware of BR. A 2012 survey of more than 700 Breast Cancer Network Australia (BCNA) members found 10% of women who had a mastectomy had never discussed BR with their surgeons and were not offered it [41], suggesting that little had changed in Australia in over 20 years. A more recent survey of BCNA members, published in 2015 [54],

Table 3 Patient-reported reasons for choosing IBR, DBR or NBR

Domain	Relevant to	Reasons
1: Feeling/looking normal	IBR and DBR	I'm too young to be without a permanent breast; to feel whole (again); to feel (more) balanced; to help forget about being a cancer victim; to avoid a period of being without a breast; to restore symmetry; to remove reminders of cancer; to look like I did before breast cancer; to look better than I did before breast cancer
2: Feeling/looking good	IBR and DBR	To maintain/regain femininity; to feel attractive (again); to help boost my self-esteem; to feel good about myself; to feel confident (again); BR is essential for my emotional well-being; to feel like I did before cancer; to feel less self-conscious during sex; to feel less self-conscious about appearance; to maintain my own sense of identity; to have more freedom to do everyday things
3: Being practical	IBR, DBR and NBR	IBR & DBR: To avoid having to wear a prosthesis/to get rid of my prosthesis; to wear the type of clothing I like; BR is essential for my physical well-being; BR is safe; it is sensible to do reconstruction with initial surgery; the cost of surgery is not an issue for me NBR: I have to travel too far for reconstruction; I do not want more surgery; I could not take time from work/family commitments; I couldn't afford it; I'm too old to have BR; I have medical reasons that excluded me from BR; BR would interrupt work, housework and parenting; I don't want the type of reconstruction offered; the risk of another operation is too high; anxiety regarding relapse and physical distress; religious reasons; don't want more surgeons/doctors visits; insufficient support at home for recovery; too much responsibility at home; live too far away for follow -up; insufficient support at home while I'm in hospital
4: Influence of others	IBR, DBR and NBR	IBR & DBR: My partner/family wants me to have BR; my surgeon strongly recommended this option; BR has been recommended to me by others; I trust my surgeon's judgement NBR: I was not given the option of BR; I was not given enough information regarding BR; my partner/family does not support me having BR; my surgeon was against BR; I do not feel comfortable asking my surgeon about BR
5: Relationship expectations	IBR and DBR	To improve relations with my partner; to improve my sexual relations; to improve my quality of life; to improve family relations; to improve work situation; to improve social relations
6: Fear	DBR and NBR	DBR: IBR is too painful; fear of additional complications associated with IBR; fear IBR might cause problems related to the cancer NBR: fear of having cancer recurrence; fear of masking cancer recurrence; fear of anaesthetic; fear of pain; fear of additional complications associated with BR; fear BR might cause problems related to the cancer; fear of unsuccessful BR; fear of being judged negatively by society for having BR
7: Timing	IBR versus DBR	IBR: To remain as normal looking as possible for my young children; to continue exercising without worrying about an external prosthesis; to make it easier to wear clothes and look normal at the beach etc.; to minimise the number of operations; to have less pain; to have a shorter recovery time; to have less time off work; to get on with life; to get back to my children; to save time; to save money DBR: I did not want more surgery (now); I only want to get rid of the cancer (now); I fear cancer recurrence; I could not take time from work/family commitments (now); the cost of surgery is an issue for me (now); I want to treat the cancer first before having BR; I am worried that radiotherapy might interfere with the BR; I want to see how all the treatment affects me before making a decision about BR; I have enough to cope with now; I didn't have a plastic surgeon; I prefer two operations rather than one long one; I prefer to spread the costs out over time
8: Unnecessary	NBR	BR is unnatural; I only want to get rid of the cancer; BR will not improve my quality of life; BR is not essential for my emotional well-being; BR is not essential for my physical well-being; I accept my body as it is; my partner accepts my body as it is; I have heard too many conflicting opinions; I don't believe the aesthetic results will be satisfactory; BR is not relevant to my body image. I don't need to look good unclothed; I don't mind wearing a prosthesis

reported only 61% of participants had an initial discussion about BR prior to mastectomy, meaning IBR was not an option for 39% of these women. This is despite only 2% of these respondents stating they were unaware of BR [54].

These results suggest a sizeable difference exists between BR knowledge and BR availability in Australia.

This finding of inadequate provision of information for women considering BR is supported by other studies

Table 4 Domains covered by publications

Authors (year) [Ref.]	Choice of reconstruction (IBR, DBR, NBR)	Type of reconstruc- tion (implant/autolo- gous)	Domain 1: Feeling/look- ing normal	Domain 2: Feeling/look- ing good	Domain 3: Being practi- cal	Domain 4: Influence of others	Domain 5: Relationship expectations	Domain 6: Fear	Domain 7: Timing OF BR	Domain 8: Unnecessary
			Relevant for IBR/DBR	Relevant for IBR/DBR	Relevant for IBR/DBR/ NBR	Relevant for IBR/DBR/ NBR	Relevant for IBR/DBR/ NBR	Relevant for DBR/NBR	Relevant for IBR versus DBR	Relevant for NBR
Adachi et al. (2007) [24] ^a	IBR/NBR	Not stated		Y				Y		Y
Alderman et al. (2011) [40]	IBR/DBR/ NBR	Not stated	Y	Y	Y	Y	Y	Y	Y	Y
Ananian et al. (2004) [19] ^b	IBR/DBR/ NBR	Not stated (surgeon's decision)		Y	Y	Y		Y		
BCNA (2011) [42]	BR (not speci- fied)/NBR	26 implant only; 11 tissue expand- ers only; 89 expander + implant; 93 TRAM; 49 lat- eral dorsi; 24 DIEP; 3 don't know	N/A [†]	N/A [†]	Y	Y	N/A [†]	Y	N/A [†]	Y
Begum et al. (2011) [25]	IBR/DBR	TRAM, DIEP, SIEP, SGAP	Y	Y	Y	Y				N/A
Clifford [43] ^c	IBR/DBR	Implants	Y	Y	Y	Y		N/A	N/A	N/A
Contant et al. (2000) [44] ^c	IBR	Silicon implants	Y	Y	Y	Y		N/A	N/A	N/A
Duggal et al. (2013) [45]	Not stated	Autologous	Y	Y	Y	Y		N/A	N/A	N/A
Elder et al. 2005 [46]	IBR	Implants	Y	Y	Y	Y		N/A	N/A	N/A
Fitzcroft et al. 2016 [37]	IBR/DBR/ NBR	27 2-stage implants; 4 direct to implant; 1 LD flap; 1 TRAM (delayed)	Y	Y	Y	Y		Y	Y	Y
Gopie et al. 2011 [47]	IBR/DBR	15 implants + 16 DIEPs	Y	Y	Y	Y		Y	Y	N/A
Handel et al. (1990) [22] ^b	BR (not speci- fied)/NBR	Not stated			Y			Y		Y
Héquet et al. 2013 [48]	NBR	N/A	N/A	N/A	Y	Y	N/A	Y	N/A	Y
Keith et al. (2003) [23] ^b	DBR/NBR	Not stated		Y	Y	Y		Y		N/A
Lam et al. (2005) [21] ^b	BR (not speci- fied)/NBR	Not stated (?) Implants	Y	Y	Y	Y		Y		N/A

Table 4 (continued)

Authors (year) [Ref.]	Choice of reconstruction (IBR, DBR, NBR)	Type of reconstruc- tion (implant/autolo- gous)	Domain 1: Feeling/look- ing normal	Domain 2: Being practi- cal	Domain 3: Influence of others	Domain 4: Relationship expectations	Domain 5: Fear	Domain 6: Timing OF BR	Domain 7: BR versus DBR	Domain 8: Unnecessary
			Relevant for IBR/DBR	Relevant for IBR/DBR/ NBR	Relevant for IBR/DBR/ NBR	Relevant for IBR/DBR/ NBR	Relevant for DBR/NBR	Relevant for DBR/NBR	Relevant for NBR	Relevant for NBR
Lardi et al. (2013) [20] ^b	DBR/NBR	DIEP only = 14; DIEP plus implants = 2; LD only = 2; LD plus implants = 1; Implants only = 7		Y	Y	Y	Y	Y	N/A	Y
Lee et al. (2010) [32] ^c	Not stated	Not stated	Y	Y	Y	Y	Y	Y		
Manne et al. 2016 [35]	BR (not speci- fied)/NBR	11 implant; 9 autolo- gous	Y	Y	Y	Y	Y	N/A	Y	
Meretoja and Suominen (2005) [49]	DBR/NBR	Not stated	Y	Y	Y	Y	Y	N/A	Y	
Morrow et al. (2014) [26] ^b	IBR/DBR/ NBR	138 implant; 84 other		Y			Y	Y	Y	Y
Neill et al. (1988) [31]	IBR	6 TRAMs; 4 saline; 1 silicone	Y	Y	Y	Y		N/A		N/A
Nelson et al. (2013) [33]	IBR/DBR	All autologous (type not stated)	Y	Y	Y	Y				N/A
Nozawa et al. (2015) [50]	IBR/DBR/ NBR	Not stated	Y	Y	Y	Y	Y	Y	Y	
Panieri et al. (2003) [51]	IBR/NBR	Not stated - TRAM was the 'most com- mon method'					Y	N/A	Y	
Reaby (1998) [34]	IBR/DBR/ NBR	Implants	Y	Y	Y	Y	Y	Y	Y	Y
Rowland et al. (1993) [52] ^c	DBR	Implants	Y	Y	Y	Y	Y	N/A	N/A	N/A
Schain et al. (1985) [53]	IBR/DBR	Implants	Y	Y	Y	Y	Y	N/A	Y	N/A
Shameem et al. (2008) [29]	IBR/NBR	? Majority were implants, but ³ women complained of ongoing donor site pain, so some autologous	Y	Y	Y	Y	Y	N/A	Y	
Somogyi et al. (2015) [54]	IBR/DBR/ NBR	140 implant; 135 autologous; 34 both	Y	Y	Y	Y	Y	Y	Y	Y

Table 4 (continued)

Authors (year) [Ref.]	Choice of reconstruction (IBR, DBR, NBR)	Type of reconstruc- tion (implant/autolo- gous)	Domain 1: Feeling/look- ing normal	Domain 2: Feeling/look- ing good	Domain 3: Being practi- cal	Domain 4: Influence of others	Domain 5: Relationship expectations	Domain 6: Fear	Domain 7: Timing OF BR	Domain 8: Unnecessary
Zielinski et al. (2014) [55]	NBR	N/A	N/A	19/27 (70%)	23/27 (85%)	25/30 (83%)	18/30 (60%)	14/27 (52%)	20/22 (91%)	8/14 (57%)

^aValue placed on particular factors/influences on BR choice^bDeterminants of choice (factors associated with a particular choice)^cGoals, motivations, concerns or expectations relating to BR[†]Reasons only given for NBR

[65–67]. However, two of the studies included in the review argued for the selective provision of information. Begum et al., in their small retrospective study of autologous BR, found that some women seek information and others avoid it, and noted the need to tailor information delivery to individuals [25]. A larger study of 101 DBR and NBR patients found that 39.5% of participants did not want information regarding the opportunities of BR, either at the time of initial diagnosis and mastectomy, or later [20]. The authors argue that counselling about BR should be available, but not obligatory, because the majority of NBR patients overcome negative attitudes towards their mastectomy quickly and are uninterested in BR. However, they noted that women who are ambivalent about BR need to be offered intensive counselling about their choice [20].

A common reason for not offering women IBR has been the predicted need for PMRT [68–70]. This in turn highlights the “significant variability” both among patients, and between patients and providers, about what matters to women most [71]. Surgeons’ concerns about the potential negative aesthetic impact of PMRT on implants may not correlate with the patient’s desire to have implant-based IBR anyway. Contant’s study reported, despite 50% of reconstructions resulting in “complications or complaints”, 70% of women were satisfied with their reconstruction and only 12% would never choose IBR again [44]. Similarly, Brennan found women are willing to accept the potential adverse outcomes of implant-based IBR following PMRT in exchange for its benefits including enhanced body image during treatment and the possible avoidance of more complicated and costly delayed autologous BR [72].

Clinicians have an ethical duty to discuss all clinically appropriate BR options with their mastectomy patients and to ensure that women have an opportunity to consider the options. Frequently, as these are complex discussions, a number of pre-operative consultations may be required as well as discussion with other professionals in the team (such as nurses or psychologists). The surgeon must also be willing to work in a multidisciplinary team with other plastic or oncoplastic surgeons, or refer the women elsewhere for treatment if she chooses a locally unavailable option.

Health system barriers do exist, but they are not impenetrable. By understanding women’s reasons for wanting or not wanting BR, or for choosing to delay that decision, clinicians can help women to make a choice that is most aligned with their individual patient’s values and needs. It will also help to inform the development of specific educational strategies for consumers and health professionals (including plastic and oncoplastic surgeons) who discuss the options with patients undergoing mastectomy.

Limitations

As with most systematic reviews, the included articles report on a range of outcomes and rely on various instruments to assess them. The majority of articles have employed qualitative methodology, which is the appropriate format to address questions about women's preferences. The major aim of this study is to better understand the reasons underlying women's choices, and the use of open questions and/or ad hoc instruments may limit the generalisability of findings. Indeed, the diversity in study designs and populations has prevented analysis about differences in reasons between age groups, ethnicity or health systems, and our findings should be interpreted carefully. Despite this heterogeneity, however, there is a strong consistency in women's reasons across studies.

Secondly, the majority of the 30 studies have come from western, high-income countries, with the exceptions of Malaysia and Poland. This is likely to reflect a paucity of BR research, and possibly BR itself, in low-income countries, and again constrains the generalisability of our findings to other settings.

A final possible limitation is the lack of validation for our assessment of study quality. The quality score does not directly reflect a particular study's limitations but rather provides a standardised measure to compare the same range of attributes across studies. A study with several specific limitations may still score highly on general attributes, while a high-quality study may not. However, the same is true of any quality measure used to assess heterogeneous studies.

Strengths of this review include rigorous methodology, incorporating a systematic search strategy and pre-defined inclusion criteria and analysis plan. The large number of participants (over 4200) across 30 studies from 13 countries provides a depth of coverage which contributes to a better understanding of the most salient issues for women faced with this decision.

Conclusion

This systematic review has provided a synthesis of the reasons underlying women's preferences regarding BR. It has demonstrated a consistency of views about what matters most to women faced with the difficult decision to have or not have BR following mastectomy for breast cancer. It has also demonstrated the utility of categorising reasons into domains. Women and clinicians may be able to focus on these eight domains in their consideration of BR options. Highlighting the paucity of genuine choice of BR, and its implications for equitable delivery of BR services, will help lay the foundations for further research and policy

advocacy into the most feasible means of increasing women's choice of BR options.

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Compliance with ethical standards

Conflict of interest All authors declare there are no conflicts of interest.

Ethics approval This systematic review was conducted under the auspices of the Improving Breast Reconstruction Equity of Access through Stakeholder consultation and Translation into Policy and Practice (I-BREAST) study. Ethics approval for I-BREAST was obtained from St Vincent's Hospital, Sydney, Human Research Ethics Committee (14/181). I-BREAST is registered with the Australian New Zealand Clinical Trials Registry (ANZCTR number 12616000188437). Separate ethics approval was not required for this systematic review.

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