

**Information needs of older women faced with a choice of primary endocrine therapy or surgery for early-stage breast cancer : a literature review**

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# Information Needs of Older Women Faced with a Choice of Primary Endocrine Therapy or Surgery for Early-Stage Breast Cancer: A Literature Review

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**Abstract** Primary endocrine therapy (PET) as an alternative to surgery is widely used in the UK for the treatment of older women with operable breast cancer. For women over 70 it has equivalent overall survival to surgery, although local control rates may be inferior. There are trade-offs to be made in deciding between surgery and PET. There has been little research to investigate the information needs of older women or the involvement in decision making they wish to have when faced with this breast-cancer treatment decision. This review examines the information needs of older women (>65 years) regarding the use of surgery or PET for treating operable primary breast cancer, and identifies their preferred format and media for the presentation of this information. The preference for involvement in treatment decision-making among this group will also be considered.

**Keywords** Breast cancer · Older women · Primary endocrine therapy · Breast surgery · Information needs · Decision making preferences · Benefits · Risks · Media · Presentation · Format

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## Introduction

Breast cancer affects 13,000 UK women over age 70 annually, and causes the deaths of 6733 per year [1]. Among patients over 70 years of age there has been less than half the reduction in cancer mortality achieved for younger women [2]. This is partly caused by variance in treatment, resulting from concerns about reduced treatment tolerance secondary to frailty and comorbidity. As a result older women may not receive chemotherapy, trastuzumab, radiotherapy, or surgery, instead being offered primary endocrine therapy (PET), which is treatment with antioestrogen tablets alone and omitting surgery altogether. PET may be an appropriate alternative to surgery for frail women and has equivalent overall survival to surgery (plus adjuvant endocrine therapy), although local disease control is inferior [3].

The choice of surgery or PET is complex. Both options are associated with advantages and disadvantages, which may vary according to health status. Surgery provides greater certainty of local cancer control but is associated with pain, temporary hospitalisation, anaesthetic risks, and a variable degree of disfigurement depending on the type of surgery. PET may be associated with a higher risk of late local disease progression, but enables avoidance of anaesthesia and surgery (which may be mastectomy or wide local excision and axillary surgery). Some older women prefer less aggressive treatments which may enable them to maintain independence and minimise potential adverse events [4, 5]. In effect, by choosing PET an older woman is trading off the risk that she may die of non-breast-cancer-related illness before her cancer becomes resistant to the anti-oestrogen treatment: this is a very difficult concept to discuss from the perspective of both the physician and the patient herself, although many older women have a very pragmatic acceptance of the inevitability of illness and death [6]. Only preliminary information on older women's

views towards PET or surgery exists, and this subject therefore requires further investigation [6].

At present, little is known about the information needs of older women diagnosed with breast cancer and their personal preferences for engagement in cancer-treatment decision making. Such information, and the production of evidence-based guidance, is needed to optimise the treatment of older women.

The purpose of this review is:

1. to investigate the information needs of older women (>65 years) regarding the use of surgery or primary endocrine therapy (PET) for the treatment of operable primary breast cancer;
2. to identify the preferred format and media for the presentation of this information;
3. to establish the preference of older women (>65 years) for involvement in treatment decision making regarding the use of surgery or PET for the treatment of operable primary breast cancer.

## Methods

### Search Strategy

A comprehensive search of the published literature was undertaken during July 2013, using the following electronic databases:

- MEDLINE
- PsycINFO
- CINAHL
- Scopus
- Web of Science
- The Cochrane Library

Three searches were performed, using the search terms below. Controlled vocabulary terms were used where available.

1. “older women” + “breast cancer” + “PET” “Surgery” “information needs”
2. “older women” + “cancer” + “information needs” review articles.
3. “older people” + “cancer” + “information needs”

Limits placed on the search were:

- Date: 1980–present day, (PET was introduced during the early 1980s).
- Participants: Humans, Females.
- Language: English.

### Inclusion Criteria

Articles were deemed to meet the inclusion criteria if:

1. They included patients with a diagnosis of breast cancer;
2. They included women over 65 years (65 is a definition of older in the UK and USA);
3. They included patients treated with surgery, primary endocrine therapy (PET), chemotherapy, and/or radiotherapy; and
4. The focus was on information needs and/or preferred media and format of information and/or preference for decision making.

### Exclusion Criteria

Articles were excluded from the review if:

1. None of the participants in the mixed cancer studies were over 65 years of age;
2. They only assessed clinical effectiveness or outcome of PET or surgery;
3. They were not in the English language.

### Results of the Search

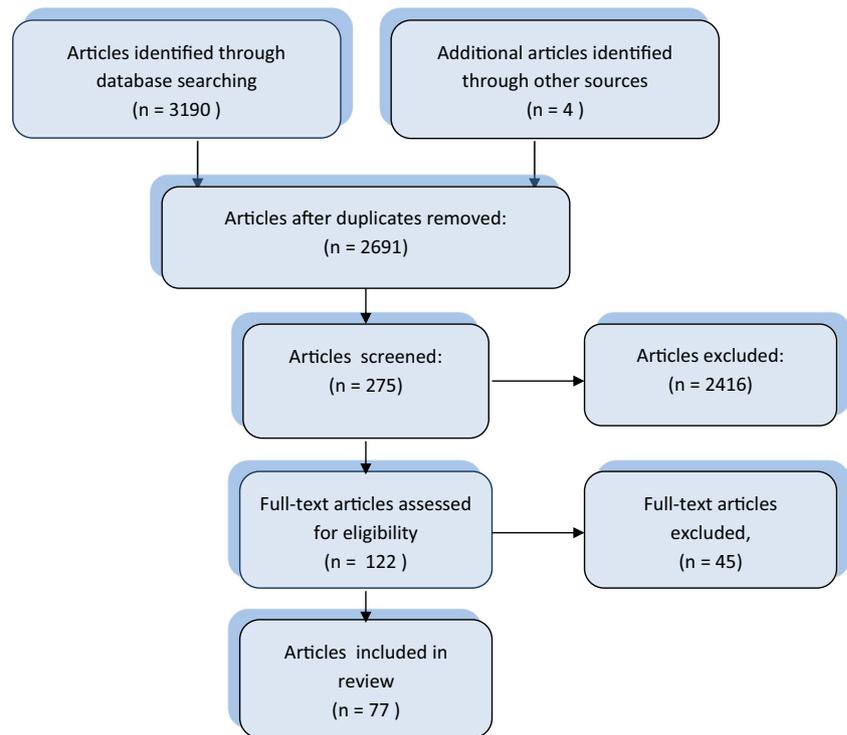
On completion of the searches, titles of papers and (where available) abstracts were scrutinised for possible inclusion in the review by one researcher (MB), and these inclusions were checked for accuracy by the second researcher (KC). Uncertainties were resolved through discussion. A total of 9767 papers were identified from the three searches.

To reduce the number of results generated from the searches, a decision was taken by the study team to focus exclusively on studies where the study sample was exclusively “breast cancer” or where the study sample was a mixed cohort but included patients with “breast cancer”.

This left 3190 papers. After removal of ineligible and duplicate abstracts, 275 titles from searches 1 and 2 were deemed potentially eligible and the abstracts were retrieved. From the abstracts 122 papers were potentially eligible and so the full article was reviewed.

Studies that focused solely on psychosocial needs, quality of life after treatment, decision-making styles, clinical outcome of surgery, or the function of health-care professionals (HCPs) in decision making were excluded. This resulted in 77 papers fulfilling the inclusion criteria and being included within the review. See Fig. 1.

Two of these papers were systematic reviews of older cancer patients, one focusing on unmet support needs of newly diagnosed patients and one focused on information needs regarding cancer, the treatment available, and the

**Fig. 1** Flow chart of review process

preference for involvement in decision making. Thirty-eight papers were breast-cancer studies of mixed-age cohorts which included a proportion of women 65 and older. A further 17 papers were cancer studies (including breast cancer) of mixed-age cohorts including a proportion of those 65 and older. Only six papers included only those aged 65 and older. Two papers focused predominantly on treatment decision making for breast cancer, and two on the information needs and two on the experiences of women with breast cancer. Only one of these papers investigated patient views on their experience of PET or surgery. Of the six papers identified, only one was UK-based. The remaining five were from Canada and the USA. See Table 1 for summary of these papers.

## Literature Review

### Information Needs of Older Women

The results below are based on all 77 reviewed articles. All papers reviewed investigated, either in whole or in part, the information needs of older patients with breast cancer. See Table 2 for a summary of identified information needs.

### Clinical and Treatment Information

At diagnosis, receiving information about the chance of a cure and the spread of the disease were the most commonly

reported concerns of most patients [7–11, 12•, 13], regardless of age. The need for medical information about the disease, the nature of breast cancer, the symptoms, the diagnostic tests, the treatment options, and prognosis were also reported to be important for older women (>70 years) with breast cancer [14, 15•, 16].

Within the identified papers, older women had a greater desire than younger women to receive information on the effect of treatment on their functional independence, self-care, quality of life [6, 8, 17, 18], and social life [19, 20]. The effect of treatment on physical appearance or surgical disfigurement and sexual attractiveness were reported by some studies to be more important to younger women [8, 12•, 20], although other studies did not support this view [21, 22].

Information on the practical aspects of treatment was also important to older cancer patients [15•, 23–25]. Difficulties of driving or transport, particularly in winter, ease and cost of parking [9, 15•], dates and times of surgery, or the timing of test results [29] were more of a concern to older patients than the treatment itself [9, 15•]. For some older patients, such factors influenced their final treatment decision [18].

### Treatment Decision Making for Older Patients

Providing treatment choice to patients presents a considerable decision-making challenge. For the older person diagnosed with cancer, it requires that they consider their own health, functional and social status, and values about quality or

**Table 1** Factors affecting the decision making of older women with breast cancer

Author Country of study	Objectives of study	Study methods, sample and age range	Key findings
Ciamborne D. (2006), USA	To identify factors associated with older women's breast-cancer primary-therapy decision-making processes. To ascertain how women's primary support persons influence decision-making processes and women's choices	30 in-depth interviews. Age range 67–90 years	<ul style="list-style-type: none"> <li>• Women trust doctor to make the right decision</li> <li>• Some want involvement in decision-making but rely on doctor to make final decision</li> <li>• Want a more active role in decision-making</li> <li>• Do not want "too many opinions" of treatment</li> <li>• Certain about the treatment they do not want, e.g. chemotherapy</li> <li>• Do not want treatment that seems debilitating</li> <li>• Age is seen, by the patient, as a reason not to have adjuvant therapy</li> </ul>
Crooks D L (2001) Canada	To investigate the assumptions made in oncology: older women just accept cancer, cannot or prefer not to make treatment decisions, are better off with extensive surgery, and breast or tissue loss is unimportant	20 in-depth interviews. Age range 66–94 years	<ul style="list-style-type: none"> <li>• Women feel supported by others in same situation</li> <li>• Prefer verbal, individualised information in non-medical language from doctor</li> <li>• Women given choices are able to choose. 2/20 felt the surgeon knew the best option</li> <li>• Choices about radiation deferred to surgeon</li> <li>• Most who refused chemotherapy had "horrible" vivid memories</li> <li>• Confusion between chemotherapy and tamoxifen</li> <li>• Women received but rejected written information that may have helped them make a decision</li> </ul>
Husain et al. (2007) UK	To investigate the views of women treated by either surgery or PET	21 semi-structured interviews. Age range 70–88 years. Median age 78 years. <15 years from diagnosis	<ul style="list-style-type: none"> <li>• Women relied heavily on medics for direction on treatment choice</li> <li>• Personal experience affected attitudes to surgery</li> <li>• No one expressed problems with PET</li> <li>• Age was said not to affect treatment choice</li> </ul>
Jing-Wen Wong et al. (2011) Canada	To investigate the information needs of women aged >70 years with early-stage breast cancer in relation to adjuvant radiotherapy post lumpectomy	One focus group and 1 interview. 15 women, age range 70–84 years. Median age 76 years Patients post-completion of radiotherapy	<ul style="list-style-type: none"> <li>• Need straightforward information on diagnosis, prognosis, grade of cancer, metastases, treatment options, and rationale for treatment</li> <li>• Need open space to allow for questions</li> <li>• Few used the internet to obtain knowledge. When used, problems with volume of material and credibility of sources</li> <li>• Practicalities, e.g. driving to treatment, created more anxiety than the radiotherapy</li> <li>• Preference for information is variable. Booklet provides information and prompts questions</li> <li>• Promoters of chemotherapy uptake: enough time to discuss side effects, benefits, and</li> </ul>
Kreling et al. (2006) USA	To understand the factors involved in older women's use or non-use of	Six focus groups. 34 women $\geq 65$ years who were eligible for chemotherapy for early-stage breast cancer.	

**Table 1** (continued)

Author Country of study	Objectives of study	Study methods, sample and age range	Key findings
Schonberg M A et al. (2012) USA	indicated adjuvant non-hormonal chemotherapy  To identify factors that influence the breast-cancer treatment decisions of women aged 80 and older	50/50 split between those who had chemotherapy and those who did not.  Medical note review. 65 women aged 80 and older. Age range 80–86 years. Median age 84 years	<p>practicalities with doctor and family; family to give emotional and decision-making support</p> <ul style="list-style-type: none"> <li>• Barriers to chemotherapy uptake: use of medical language; hurried appointments; too much general information not specific enough for individual</li> <li>• Chemotherapy often thought to be not as bad as expected</li> <li>• Factors which influence women included: family involvement, side effects, religious belief, previous experience of cancer treatment efficacy, physician's opinion</li> <li>• 10/65 women initially did not want aggressive treatment but agreed to it after discussion with physician</li> <li>• 2/65 women wanted as aggressive a treatment as possible from the outset</li> </ul>

quantity of life [27]. Extrinsic factors including the information received and the opinions of health-care professionals and family and friends all contribute to the decision-making process. There is evidence that patient involvement in treatment decision making usually increases treatment satisfaction and reduces anxiety and depression [28–31]. Three main patient decision-making styles have been described: active, those who wish to make their own healthcare decisions; collaborative, those who wish to share decision making; and passive, those who defer decision making to others [32]. Breast-cancer patients generally (not specifically older women) increasingly prefer more active and collaborative roles in treatment decision making [32, 33], although some prefer to defer decisions to others [28, 29, 34, 35]. A recent UK study reported the preferred decision making styles of women with breast cancer

**Table 2** Summary of findings

**Information desired on disease and treatment**

- Chances of cure, spread, or recurrence of disease, and prognosis
- Understanding the diagnosis and the rationale for treatment
- Recommended treatment plan
- Effectiveness and side effects of treatment options
- How to avoid and relieve side effects
- Effect of treatment on self-care, independence, and social life
- Effect of treatment on emotional wellbeing and psychosocial aspects
- Practical information, e.g. transport, important in deciding on treatment

**The level and amount of information**

- Preference for amount of information highly variable
- Information provision to be tailored to the individual's situation and preferences
- Limited need for large volumes of general information
- Personal stories of others in similar circumstances are appreciated by some

**Receiving information**

- Simple booklets, jargon-free language, and simple diagrams are preferred
- Preference of words to numbers to describe or quantify risk
- Verbal information preferred, preferably from the treating clinician
- Time given during consultation to ask questions
- Information provision needs to change over the treatment pathway

**Sources of information**

- Health-care professionals believed best source of information
- Written information poorly used
- Family and friends a further source of information for some
- The internet used by a minority to find health information

**Decision making**

- Patients may want to play an active part in the decision-making process
- With increasing age there is a trend towards relying on the surgeon for the decision
- Not all older breast-cancer patients want a passive role
- Patient preference for decision making should be investigated
- Older breast-cancer patients frequently make decisions on the basis of limited, inaccurate knowledge

by mean age. Those who preferred an active role were on average 57.4 years, those preferring a collaborative role were on average 58.4 years, and those preferring a passive role were on average 61.1 years; less than 20 % of women preferred to defer their treatment decision to others. However, the average age of participants in this study was much younger than 70 (mean age 58.5, with only 10.7 % over 70 years) and the results may therefore be irrelevant to this older age group [32].

There is limited evidence on which to assess the preferences for treatment decision making of older women with breast cancer; however, the evidence suggests that older patients are more passive in their decision making than their younger counterparts [6, 13, 32, 36, 37]. Breast-cancer patients, regardless of age, frequently consult family and friends, who provide anecdotal and possibly erroneous information [38], and tend to delegate responsibility for decisions to their doctors, family, and friends [5, 38–40]. Personal experience of others' cancer is also a factor which affects knowledge of cancer treatments [6]. There is unclear evidence on the use of other media, including newspaper and television, in information seeking and decision making. Mills and Davidson [41] found that television and radio are infrequently used by those over 65 years, but Hughes [42] reported that lay media may be one of the top three sources for information. Talosig-Garcia and Davis [43] found newspapers and magazines to be a very helpful source of information for women.

An American study of 1131 patients with breast cancer, of whom 249 were over 70, revealed a high level of involvement in treatment decision making (52 %), with approximately half the women stating that they had the right amount of involvement [44]. However, over 40 % felt they had too much involvement and a small percentage felt they had too little involvement (7.6 %). Overall the researchers concluded that involvement did not vary with age but there was a trend for less involvement with increasing age. This conclusion was supported by Han et al. [45].

A study of healthy individuals concluded that most women prefer clinical decisions to be taken by their doctor, and that past the age of 45 the desire for participation in treatment decision making decreased [46].

Patients may want to be fully informed and participate in the decision-making process by making their preferences, values, opinions, and fears known regardless of age [18, 22, 23, 47, 48]. However, there is a trend for older patients to prefer the surgeon to make the final treatment decision [11, 20, 22, 45, 49], and this seems to be related to the severity of their illness [50]. Where best practice is known, surgeons are confident in recommending a particular intervention; however, where best practice is unclear surgeons more frequently invite the patient to choose [26].

## Factors Affecting Treatment Choice

Only one study [6] was identified that examined the factors affecting the treatment decisions of older women faced with a choice of surgery or PET for the treatment of breast cancer. In this study 21 purposively selected breast-cancer patients, who had been treated with either PET or surgery, took part in in-depth qualitative interviews. This study found that the women relied heavily on health-care providers for information; however, this information was not used to make the treatment decision. Women were reported to be listening for cues from the medical team to detect what was being recommended. In line with other studies, the women did not actively question the information given to them by the doctor. A small number of women actively chose treatment contrary to the advice of the medical team, and their decision was on the basis of family experience of breast cancer. Avoidance of surgery was not a factor for women choosing PET; however, previous painful biopsies were a consideration.

## Amount and Level of Information

Patients with cancer have high information needs and the same is true for breast cancer, irrespective of patient age [51–53, Caldon L, PhD thesis 2011 “Patient and Clinician factors influencing the choice of breast cancer surgery: a qualitative and quantitative study”, unpublished data]. Information is a pre-requisite for informed decision making [34, 51, 54]. The type, amount, and level of information preferred differs across the treatment pathway and between individuals [16], and the amount of information collected does not always correlate with the desire to make decisions [4, 17, 49, 55] or with the patient's preferred decision-making style [7, 22, 34, 55]. The amount of information older patients require to make a treatment decision is variable [56]. Some older patients find the type and amount of medical information they receive overwhelming [23], and they have fewer information needs [19]. Others want as much information as possible to help them better understand their treatment options and the rationale for treatment [15, 26]. Other studies report older patients having a lower need for information [11, 12, 14], with a meta-analysis revealing a trend towards younger patients preferring a more active decision-making role and having a greater need for information [57]. In contrast, Cox et al. [22] found little or no difference in the need for information between younger and older patients. Several authors have concluded that information about breast-cancer treatment options needs to be age specific, relevant, and tailored to the patient [15, 23, 47, 58].

Older women rely primarily on the information given by their clinician or breast-care nurse, and subsequently on information given by their family, to make decisions about their treatment [6, 48, 59, 60]. Older women are also less likely than their younger counterparts to question their clinician to gain

further information regarding different treatment options [5]. However, given adequate time during the consultation older patients do seem to seek more detailed information about their condition [59–61]. Older women require information that is simple, balanced, and in sufficient detail to enable them to reach an informed decision independently [15•]. Specific information regarding age-specific incidence, risk factors for breast cancer in older age, signs and symptoms of breast cancer, breast-cancer treatment options, and age-specific prognostic information was most highly regarded [15•].

### Pacing of Information

Older cancer patients prefer paced information which is repeated to allow time for assimilation [22], with information provided throughout the treatment pathway as information needs change [14]. Patients' recall is impaired in life-threatening situations [42, 62], and information absorption is hindered when individuals are provided with information they find difficult or unpleasant [62] or when they are overwhelmed by the provision of excessive information in a single consultation [64]. Patients' recall is better for information provided at the start of a consultation [64]. Despite barriers, for example to the patient's ability to absorb and recall information when confronted by a diagnosis of cancer, the information that is recalled can persist and gain importance over time, with older patients quoting their clinicians verbatim [63]. Fallowfield et al. [64] proposed that "...information needs to be given systematically, at the right time and via several different routes, to maximise the chances for patients to understand the implications and make really informed choices" [65].

### Preferences for Format and Media of Information

Older patients prefer information to be given to them verbally by their treating clinician [51, 53, 65]. However, study findings consistently suggest that clinicians often underestimate patients' information needs [8, 66–69]. A recent study of the use of information technology found that only 15 % of the UK population of older people (i.e. those aged 60 and older) had access to a computer. Use of the internet remains low, with only 14 % of adults over 70 years using it for seeking health information [70]. Couper et al. [71] reported that older people (aged over 70) tended to use their computer for word processing and not as a source of information for such complex subjects as breast cancer. Those who did use the internet either rated the information highly but only as a supplement to that provided by the health-care provider, or reported that they struggled with the volume of information and knowing how to assess its credibility [15•]. In summary, the internet has been revealed to be rarely used by the older population to access breast-cancer treatment information [43].

Presenting complex material to older patients who possibly have declining cognitive function is a substantial challenge. Although there is a correlation between comprehension and literacy across all age groups, when compared with a younger age group older adults have poorer numeracy and comprehension of written information [12•, 47, 70, 72–74]. Other factors, including poor hearing and eyesight, may also affect the ability of older patients to make an informed treatment decision [74, 75].

When people have little or no understanding of the choices being presented, it is difficult for them to have any real understanding of the consequences of a choice and what effect it would have on their lives. The use of narratives or stories has been revealed to enhance the ability to assess attributes and weigh them in decision making. Where tables and graphs were used, older breast-cancer patients needed an explanation of the data in order for it to have meaning to them [74] and for them to make a better judgement regarding a treatment choice [73, 76, 77]. The provision of personal cancer stories within the information was also regarded as useful in helping them understand and cope with the disease and its treatment [15•, 21]. The combined use of anecdotes and pictograms was reported to enhance understanding and decision making among women aged under 79 years diagnosed with breast cancer [78].

Simple booklets [50] with short explanations of risks and benefits of treatment, free of medical language and with clear diagrams [15•, 21], were requested by older women undergoing adjuvant therapy. It was found that older women did not respond well to complex information and that the heterogeneity of the population would necessitate many different formats.

Tailoring or customising information also reduces cognitive load. Stories or narratives based on the experiences of people like themselves emphasise the meaning a choice would have on women's lives. This is particularly effective when the story triggers a memory [79]. Tailored health materials are reported to be more effective than general material at enhancing behavioural change [76].

Evidence suggests that presenting risks and benefits to experts and the general public as frequencies rather than probabilities is more meaningful and carries more weight in decision making [76]. This is contrary to the findings of Fausset and Rogers [74], who report that older people (mean age 71, range 65–75) performed better using percentage values than frequencies. In the Hughes study [42] of a younger population (mean age 41, range 21–80) choice of treatment was unrelated to the way the information was presented. There was no difference in choice of mastectomy or breast-conserving surgery whether description or probabilities were used to present risk.

The framing of information provision also affects the meaning older patients attribute to it. A review by Edwards

et al. [80] examining the effect of framing of risk information concluded that the evidence of the effect of framing was weak. There was some indication of framing increasing the uptake of detection behaviours, e.g. screening. There was also limited evidence to suggest patients choose what might be perceived as risky treatments when information is positively framed. Although this review examined clinical studies the results were not stratified by patient age.

Graham, Martin and Browne [81] studied 262 women (no age range given) with breast cancer to identify their preference for language, percentages, or numbers in describing the risk of treatment. Fifty-two percent preferred language and 48 % numerical expression (21 % numbers and 27 % percentages) to describe risk. Those who were younger, i.e. below the mean age of 62, and were more highly educated preferred numerical representation. Strategies suggested included diagrams and risk–benefit tables to aid conceptualisation. Problems around credibility of information given and how to filter the volume of information available were raised. Edwards et al. [80] found no evidence of effect in the way data were presented.

## Conclusions

There is a dearth of evidence on the information needs of older women when faced with a choice of PET or surgery for early-stage breast-cancer treatment. Similarly, there is little information on the preferred format, presentation, or media, nor on the preferred involvement in treatment decision making of older women with breast cancer.

There is some agreement about the required type of information relating to breast cancer and its treatment, and on how this needs to be delivered across the treatment pathway. Information on the effect of the treatment on self-care, physical function, and quality of life seems to be universally desired by older women.

There is limited evidence on which to assess the preference for treatment decision making of older women with breast cancer; however, the evidence suggests that older patients are more passive in their decision making than their younger counterparts [6, 32, 36, 37].

One of the objectives of providing information is to enable women to make informed decisions about their breast-cancer treatment. Patients may want to be fully informed and to participate in the decision-making process by making their preferences, values, opinions, and fears known [18, 22, 23, 47]. However, there is a trend for older patients to prefer the surgeon to make the final treatment decision [11, 20, 22, 45, 49].

The main source of information is the health-care provider: either the clinician or breast-care nurses. There is a preference for personalised information received verbally. The internet is

not widely used by older patients. Written information is the usual format preferred. Simple booklets using clear, jargon-free language are preferred, with the addition of uncomplicated diagrams and stories of women in a similar situation. In describing risk and benefit, there is some evidence that words are preferred to numbers.

The evidence presented is on the basis of limited literature and so cannot be relied upon to give an accurate or complete picture. High-quality research is required to establish the information needs of older women, specifically those over 70 years, their preferences regarding format and media, and their preferred level of treatment decision making when faced with a choice of treatment for early-stage breast cancer.

## Compliance with Ethics Guidelines

**Conflict of Interest** Maria Burton, Karen Collins, Lynda Wyld, and Malcolm Reed declare that they have no conflict of interest. Lisa JM Caldon reports grants from NIHR, during the conduct of the study.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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