



# Acceptability of a companion patient guide to support expert consensus guidelines on surveillance mammography in older breast cancer survivors

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## Abstract

**Purpose** To support shared decision-making, patient-facing resources are needed to complement recently published guidelines on approaches for surveillance mammography in breast cancer survivors aged  $\geq 75$  or with  $< 10$ -year life expectancy. We created a patient guide to facilitate discussions about surveillance mammography in older breast cancer survivors.

**Methods** The “Are Mammograms Still Right for Me?” guide estimates future ipsilateral and contralateral breast (in-breast) cancer risks, general health, and the potential benefits/harms of mammography, with prompts for discussion. We conducted in-clinic acceptability testing of the guide by survivors and their clinicians at a National Cancer Institute-designated comprehensive cancer center, including two community practices. Patients and clinicians received the guide ahead of a clinic visit and surveyed patients (pre-/post-visit) and clinicians (post-visit). Acceptability was defined as  $\geq 75\%$  of patients and clinicians reporting that the guide (a) should be recommended to others, (b) is clear, (c) is helpful, and (d) contains a suitable amount of information. We also elicited feedback on usability and mammography intentions.

**Results** We enrolled 45 patients and their 21 clinicians. Among those responding in post-visit surveys, 33/37 (89%) patients and 15/16 (94%) clinicians would recommend the guide to others; 33/37 (89%) patients and 15/16 (94%) clinicians felt everything/most things were clear. All other pre-specified acceptability criteria were met. Most patients reported strong intentions for mammography (100% pre-visit, 98% post-visit).

**Conclusion** Oncology clinicians and older breast cancer survivors found a guide to inform mammography decision-making acceptable and clear. A multisite clinical trial is needed to assess the guide’s impact mammography utilization.

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**Keywords** Mammogram · Mammography · Older breast cancer survivors · Decision-making · Guide

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## Introduction

Developing strategies to optimally support older breast cancer survivors is highly relevant to clinical practice, with more than 1.5 million breast cancer survivors aged  $\geq 75$  currently living in the U.S [1–4]. This number is anticipated to grow as the U.S. population ages and breast cancer mortality improves [1–4], yet guidelines for breast imaging in older breast cancer survivors [5] lack individualization or incorporation of life expectancy. Although *screening* mammography guidelines (for women without a history of breast cancer) recommend discontinuation of routine testing (i.e., in absence of symptoms or exam findings) when life expectancy is limited [6, 7], survivorship guidelines do not address how to tailor surveillance mammography by life expectancy [8, 9]. Thus, it is not surprising that conversations occur infrequently in clinical practice [9], with high utilization of surveillance mammography even when life expectancy is short [10].

We recently published expert consensus guidelines and talking points focusing on the older breast cancer survivor, with suggestions on how to approach surveillance mammography in the context of one's life expectancy, age, the anticipated benefits and harms of testing, and patient preferences [9]. The guidelines acknowledge the long time-lag required to achieve minimal benefits in breast cancer-specific mortality from mammography [6, 11] and the more immediate harms of testing (e.g., false positives, overdiagnosis, over-treatment). As those guidelines were designed to support clinicians, they did not include patient-facing educational materials.

Engaging patients in patient-centered decision-making [12, 13] can ease exaggerated perceptions of cancer risk, provide reassurance, promote autonomy, and support clinicians by providing talking points for topics that may be uncomfortable, such as discontinuing a test to which patients/clinicians feel attached. Thus, shared decision-making has emerged as an effective approach for de-implementation of testing [14–16], particularly when benefit-to-harm ratios are uncertain or when benefits are outweighed by harms, such as the case of surveillance mammography for those with limited life expectancy. The value of shared decision-making in de-implementation has been demonstrated for *screening* mammography in primary care settings, facilitating informed decision-making, reduction in over-screening, improved patient knowledge, and satisfaction [16–27].

Recognizing the lack of decision support for older breast cancer survivors and their clinicians around *surveillance* mammograms, we created a patient-facing guide to complement the expert consensus guidelines [9]. Herein,

we present results from acceptability testing of the “Are Mammograms Still Right for Me?” guide.

## Materials and methods

### Guide creation

We first obtained broad feedback on the guide's content from multidisciplinary clinicians and patient advocates serving on our expert consensus panel and from primary care and oncology clinicians participating in five focus groups during guideline development [9]. In collaboration with the Dana-Farber Cancer Institute (DFCI) Health Communications Core, we then created a four-page “Are Mammograms Still Right for Me?” informational pamphlet (also available as a PDF file; shown in its final, revised form in Supplemental File S1), which applied the fundamental theory from the Ottawa Decision Framework [28] and which adapted a decision aid developed for screening mammography [16, 19, 26, 27].

The guide was prepared for an 8<sup>th</sup> grade reading level (per Flesch-Kincaid literacy criteria) [29], providing information specific for older breast cancer survivors on: (a) why mammography is a decision, (b) estimations of ipsilateral and contralateral breast cancer risk, including risk for recurrences or new primary cancers (i.e., ‘in-breast’ cancer) risks, (c) potential benefits/harms of mammography, (d) how overall health impacts surveillance mammography's benefits [9], and (e) discussion prompts for ‘what's important to you?’, encouraging patients to use the guide to deliberate with clinicians. The guide has bulleted text and short sentences to enhance readability, uses pie charts to display the risks for in-breast recurrences and new primary cancer events, and aims to provide a balanced list of the benefits/harms of mammography. The guide's estimation of in-breast cancer risks is derived from a comprehensive literature review and is based on one's personal cancer and treatment history [8, 9].

In preparation for in-clinic acceptability testing, we conducted fifteen semi-structured telephone interviews with breast cancer survivors aged  $\geq 75$ . We elicited input on the guide's content and clarity, while also eliciting intentions (or plans) for mammography and conversations about life expectancy (since one's life expectancy informs high-quality mammography decision-making). Overall, participants provided affirmative feedback on the guide's format, length, and content. Because there were no consistent concerns identified, the guide was not modified before in-clinic testing. This research was approved by the DFCI Office of Human Research. Informed consent was obtained from all individual participants included in the study.

## In-clinic acceptability testing—approach

We included breast cancer survivors who were aged  $\geq 75$  (where discontinuation of mammography may be appropriate given median U.S. life expectancy of  $\sim 10$  years at age 75) and who received care at DFCI (Boston, MA) or two community-based satellite practices (Weymouth and Brighton, both in MA). All patients had to have completed active treatment(s) for their breast cancer (endocrine therapy allowed) and were required to read/speak English. We conducted feasibility testing in oncology practices because in prior focus groups of oncology and primary care clinicians, we learned that primary care clinicians defer to oncologists for decision-making around mammography [9].

Trained clinical research coordinators (CRCs) scanned clinic schedules for the upcoming four to six weeks to identify potentially eligible patients. Because we enrolled during the COVID-19 pandemic, we allowed virtual visits. Visit clinicians (physicians, nurse practitioners, physician assistants) were notified about plans to approach each patient and were allowed to opt out (no clinicians opted out). The CRC then contacted the patient to explain the study's purpose and obtain verbal consent. Once enrolled, patients were mailed or emailed the guide; visit clinicians were notified.

The day before the visit, the CRC reminded the patient and clinician about the visit, encouraged them to use the guide during the visit, and administered the pre-visit survey to the patient. The survey was adapted from those used in mammography screening settings [16] and included questions about mammography intentions [19, 30], decisional conflict [31–33], demographics, numeracy [34], and health literacy [35], using validated scales and definitions (eTable 1). In addition, because the patient guide was designed to complement expert consensus approaches to mammography that emphasize considerations of life expectancy, we surveyed patients' comfort level and preferences regarding life expectancy discussions. After the clinic visit, the CRC administered the post-visit survey within a week (with up to three reminders) and provided a \$40 gift card, concluding study participation. The patient post-visit survey included items similar to pre-visit surveys plus acceptability questions about the guide (discussed below). We surveyed all clinicians via email following each visit, asking questions on guide acceptability, intentions (or plans) for mammography for that patient, and comfort with life expectancy discussions. Participating clinicians received a one-time \$25 gift card at end-of-study. All patient and clinician surveys were administered via REDCap.

## In-clinic acceptability testing—analyses

Our primary endpoint was guide acceptability, defined as  $\geq 75\%$  of unique patients *and* clinicians reporting *each*

of the following responses in post-visit surveys: (a) would recommend use by others, (b) clear or mostly clear in its explanations, (c) helpful, and (d) with a suitable amount of information (right amount, a little more, or a little less information than needed). We tabulated responses to these questions on post-visit patient and clinician surveys; all analyses for the primary endpoint were descriptive.

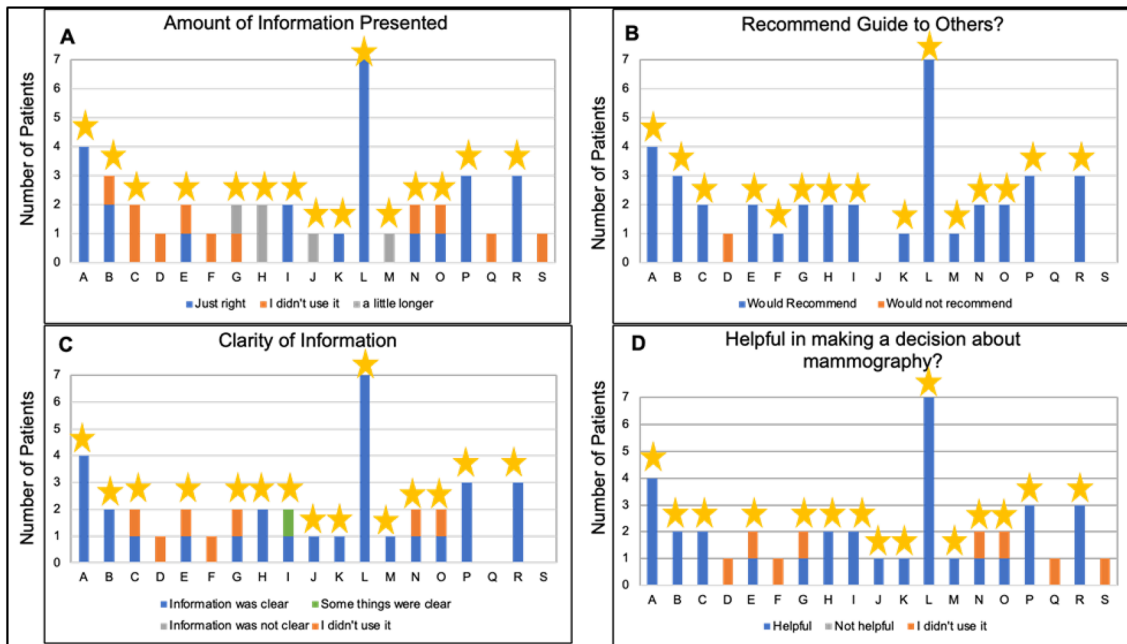
For clinician acceptability, we examined responses to each relevant question by clinician (up to 19 submitted surveys, designated as clinicians A-S in Fig. 1). If a clinician stated that they did not use the guide with one patient but then used it with a second patient and rated it favorably, we counted the response provided for the second patient towards acceptability. Clinicians who never used the guide (e.g., clinician D) were not included in the denominator assessing acceptability.

*Pre-visit* patient surveys collected demographics, health literacy, numeracy, and preferences for decision-making roles. *Post-visit* surveys included general guide feedback (e.g., length, clarity). Both surveys inquired about intentions for mammography plus past and current (study visit) experiences and comfort level with life expectancy discussions.

From *post-visit* clinician surveys, in addition to acceptability, we described clinician responses for each participating patient for questions that were relevant to a particular patient (e.g., “What did you recommend in terms of mammograms for *this* patient?”, “Did you discuss the pros [and cons] of mammography”). In addition to descriptive analyses and extraction of explanatory comments (when provided), we used t-tests to examine changes in patient decisional conflict around mammography from the pre- and post-survey to inform design of a future trial of the guide. All analyses were conducted using SAS.

## Results

Among 88 patients approached between August 18, 2019 and May 11, 2020, 18 declined enrollment, 22 could not be reached, three were ineligible, and 45 women enrolled; no clinicians opted out for their patients. The 45 patient participants (ages 75–92, median = 78 years) had clinic visits with 21 unique oncology clinicians (six nurse practitioners, one physician assistant, 14 physicians); participating clinicians had one to seven patients who enrolled. Of the 45 enrolled patients, 40 completed at least some of the post-visit survey (three could not be reached, one rescheduled her visit twice and never completed the survey, one declined). Among 21 clinicians, 19 completed at least one survey. Patient characteristics are summarized in Table 1; 43 (96%) of patients reported White race, five (11%) reported a high school degree as their highest education, and two (4%) reported feeling extremely good about working with



Labels A-S on x-axis correspond to each clinician ( $n=19$ ); clinicians not answering questions shown are left blank.

Yellow stars indicate when a clinician was counted towards definition of acceptability for each question

**Fig. 1** Responses for acceptability of the patient guide by clinician ( $n=19$ )

fractions, reflecting high numeracy. One woman reported ever having conversations about life expectancy, although 19 (42%) expressed interest in knowing this information, particularly if life expectancy was < one year. Extreme worry regarding new breast cancers was infrequent.

## Acceptability

Acceptability of the guide by patients (Table 2) and clinicians (Fig. 1) was high; overall, clinicians were consistent in post-visit responses across patients. Among patients and clinicians completing post-visit surveys, 33/37 (89%) patients and 15/16 (94%) clinicians stated they would recommend the guide to others; 33/37 (89%) patients and 15/16 (94%) clinicians reported that everything/most things were clear (including one clinician who answered ‘most things were clear’ for one patient and ‘some things were clear’ for another). In addition, 20 patients (54%) and 96% of clinicians reported that the amount of information provided was suitable. Finally, 84% of patients and 80% of clinicians reported the guide was helpful in making decisions about mammography. All of these responses met prespecified criteria for acceptability.

*Additional clinician feedback* (Table 3).

Overall, clinician feedback on the guide was positive, with 73% stating the length was ‘just right’ and only two clinicians preferred a format other than a printed pamphlet. Several clinicians provided written comments: “...*the guide is absolutely wonderful*”, and “*It would be great to have this...readily available for...discussions with our older patients.*” Only one clinician reported that the guide made the visit a ‘lot longer’: “*I worry about the ability of busy clinicians to use it during their constrained visits.*” Even when clinicians recommended that a participating patient continue mammography, open-ended comments acknowledged (a) the general appropriateness of these discussions, (b) the importance of patient preferences, and (c) when it may not be appropriate to have these discussions.

Clinicians did not use the guide in 22% of visits, with some stating that patients required additional testing ( $n=3$ ) or were recommended to continue mammography ( $n=4$ ) because of higher-than-average risk for future in-breast cancers, excellent life expectancy, or patient preferences: “*My bias was against recommending mammograms...the guide helped us think clearly about pros/cons in a very healthy patient with history of bilateral breast cancers who is more reassured to continue mammograms.*” Another clinician stated: “[*T*]here are many patients who you already know will want to continue due to high anxiety.” Overall, patient

**Table 1** Patient participant characteristics from pre-visit survey for in-clinic acceptability testing ( $n=45$ )

Patient characteristics	n (%) unless otherwise specified
<i>Age, years (range 75–92, median = 78, mean = 79)</i>	
75–79	32 (71)
80–84	10 (22)
85 or older	3 (7)
<i>Which race do you most identify with?</i>	
White or Caucasian	43 (96)
Black or African American	1 (2)
Asian	1 (2)
<i>Marital status</i>	
Single, never married	3 (7)
Married	26 (58)
Divorced or widowed	16 (36)
<i>What is the highest level of school you completed or highest degree you have received?</i>	
High school graduate	5 (11)
Some college	12 (27)
Bachelor's degree	7 (16)
Master's degree, professional degree, nursing degree, doctoral degree	21 (47)
<i>How would you describe your household's financial situation right now?</i>	
After paying the bills, you still have enough money for special things that you want	32 (74)
You have enough money to pay the bills, but little spare money to buy extra or special things	7 (16)
You have money to pay the bills, but only because you have cut back on things	3 (7)
You are having difficulty paying the bills, no matter what you do	1 (2)
No response	2 (4)
<b>Health literacy and numeracy</b>	
Not at all confident to somewhat confident in filling out medical forms by yourself[35]	8 (18)
<i>How good are you at working with fractions [34]?</i>	
Extremely good	2 (4)
Very good or good	20 (45)
Somewhat good or a little bit good	19 (42)
Not at all good	4 (9)
<i>How good are you at calculating a 15% tip [34]?</i>	
Extremely good	13 (29)
Very good or good	25 (56)
Somewhat good or a little bit good	6 (13)
Not at all good	1 (2)
<i>When people tell you the chance of something happening, do you prefer that they use words ("rarely happens") or numbers ("a 1% chance") [34]?</i>	
Always prefer or most of the time prefer words	22 (49)
Sometimes prefer words or sometimes prefer numbers	11 (24)
Always prefer or most of the time prefer numbers	12 (27)
<b>Preferences for decision-making and worry</b>	
<i>What is your preferred role in decision-making around mammography [36]? I prefer...</i>	
...to make the final decision	14 (31)
...to make the final decision after seriously considering my health care provider's opinion	15 (33)
...that my health care provider and I share responsibility for deciding	13 (29)
...that my health care provider makes the final decision, but seriously considers my opinion	3 (7)
...to leave all decisions regarding mammography to my health care provider	0 (0)
On a scale of 1–6, with 6 being the most worried and 1 being the least worried, how much do you worry about your cancer coming back [37, 38]?	Median = 3 (range 2–6)

**Table 1** (continued)

Patient characteristics	n (%) unless otherwise specified
On a scale of 1–6, with 6 being the most worried and 1 being the least worried, how much do you worry about needing more tests after you have a mammogram [37, 38]?	Median = 2 (range 1–5)
On a scale of 1–6, with 6 being the most worried and 1 being the least worried, how much do you worry about getting another cancer besides breast cancer [37, 38]?	Median = 3 (range 1–6)
<i>How do you prefer to receive health educational materials in general?</i>	
Paper	17 (38)
Computer/internet	10 (22)
Web-based or mobile application	2 (4)
No preference	13 (29)
<b>Life expectancy-related questions</b>	
<i>Have any of your health care providers ever talked to you about how much time you have left to live?</i>	
Yes	1 (2)
No	44 (98)
If your health care providers could estimate how long you may have to live based on your current health status, would you want them to tell you?	
Yes	19 (42)
No	14 (31)
I don't know	12 (27)
<i>We have no idea how long you will live. We would like to give you a made-up example. Let's say your health care provider thinks you have &lt; 5 years to live. Would you want to know?</i>	
Yes	19 (42)
No	14 (31)
I don't know	12 (27)
<i>We would like to give you another made up example. Let's say your health care provider thinks you have less than 1 year to live. Would you want to know?</i>	
Yes	32 (71)
No	6 (13)
I don't know	7 (16)
<i>Would having this information help you make decisions about your health care?</i>	
Yes	38 (84)
No	4 (9)
I don't know	3 (7)

All 45 patients filled out pre-visit surveys; those not providing responses or answering 'I don't know' are shown in the table for relevant questions

preferences were strong for mammography (see below); five clinicians reported that they would have recommended discontinuation of mammography before the visit, but only one clinician reported recommending discontinuation after the visit.

Overall, in 29/41 visits (71%), clinicians reported discussing the pros and cons of mammography and less commonly life expectancy (18/41 visits [44%]). Most clinicians found the guide helpful, and none reported uncomfortable conversations (though one perceived the patient as uncomfortable): "...This tool makes it easier to discuss comorbidity and life expectancy; less awkward", and "...having a printed tool made the life expectancy discussions...comfortable...It made it less like I had some specific concern that I was bringing up; the discussions are more just a part of standard

practice." For those not discussing life expectancy, the most common reasons provided were "it didn't come up" or the "patient was healthy, so I didn't think it was important."

*Mammography intentions and additional patient feedback* (Table 2 and eTable 2).

Intentions for mammography were very strong in patient pre- (100%) and post- (98%) visit surveys, with only one patient deciding to discontinue mammography after the visit (her clinician also recommended discontinuation). Patients had low decisional conflict on pre- and post-surveys, with mean total scores of 12.8 and 12.0, respectively ( $p=0.79$ ; eTable 2). Overall, in post-clinic surveys, 22 patients (56%) recalled discussing mammography's benefits, eleven (29%) reported discussing mammography's cons, and nine (23%) recalled life expectancy discussions (Table 2). Although one

**Table 2** Acceptability and feedback on visit and patient guide (patient post-visit survey,  $n=40$ )

Questions and responses	(N, %) <sup>a</sup>
<b>Feedback on the guide</b>	
<i>How helpful was the guide in making a decision about mammography?</i> <sup>b</sup>	$N=37$
Very, somewhat, or a little helpful	31 (84)
Not helpful	6 (16)
<i>Would you recommend the use of the guide?</i> <sup>b</sup>	$N=37$
Recommend (definitely or probably)	33 (89)
Would not recommend (probably not recommend [ $n=4$ ]; ‘definitely not’ [ $n=0$ ])	4 (11)
<i>How clear was the information?</i> <sup>b</sup>	$N=37$
Everything was clear or most things were clear	33 (89)
Some things were clear	3 (8)
Many things were unclear	1 (3)
<i>The amount of information was...</i> <sup>b</sup>	$N=37$
Much less than I needed	1 (3)
Suitable amount (a little less than [ $n=7$ ], just right [ $n=20$ ], or a little more than I needed [ $n=8$ ])	35 (95)
Much more than I needed	1 (3)
<i>The length of the guide was...</i>	$N=37$
Much too long	2 (5)
A little too long, just right, a little too short	33 (89)
Much too short	2 (5)
<i>I found the information:</i>	$N=40$
Clearly slanted towards getting a mammogram	7 (20)
A little slanted towards getting a mammogram	6 (17)
Completely balanced	16 (46)
A little slanted towards NOT getting mammogram	4 (11)
Clearly slanted towards NOT getting a mammogram	2 (6)
<i>Reading the information made me feel...</i>	$N=38$
Not anxious at all	28 (74)
A little anxious	9 (24)
Very anxious or as anxious as I could be	1 (3)
<i>Check the most accurate statement below:</i>	$N=37$
I understood none of the information	1 (3)
I understood a little of the information	2 (5)
I understood most of the information	15 (41)
I fully understood all of the information	19 (51)
<i>What is your preferred format for health education materials?</i>	$N=39$
A pamphlet like the one you included in this study	14 (36)
Computer/internet	9 (23)
No preference	12 (31)
Other	4 (10)
<i>Preparation for decision scale (10 questions)</i>	$N=36$
Mean (Range) <sup>c</sup>	58 (0–100) <sup>c</sup>
<b>Clinic visit discussions</b>	
<i>At the visit, did you talk to your health care provider about getting a mammogram?</i>	$N=39$
Yes	28 (72)
<i>Did your provider talk to you about the benefits of getting a mammogram?</i>	$N=39$
Yes	22 (56)
<i>Did your provider talk to you about any downsides of getting a mammogram?</i>	$N=38$
Yes	11 (29)
<i>What did your provider recommend in terms of mammograms?</i>	$N=38$
Continue having mammograms	27 (71)

**Table 2** (continued)

Questions and responses	(N, %) <sup>a</sup>
Get another one but consider stopping after that	3 (8)
It is my choice	7 (18)
To not get one now but consider later	0 (0)
To stop getting mammograms	1 (3)
<i>Did your health care provider or nurse discuss your life expectancy with you today?</i>	<i>N=40</i>
Yes	9 (23)
<i>If yes, (n = 9 from above), how did it make you feel? (not mutually exclusive)</i>	<i>N=9</i>
Comfortable	5 (56)
Uncomfortable	1 (11)
Informed	6 (67)
Content/happy	2 (22)
Calm	3 (33)
Interested	3 (33)

<sup>a</sup>among those who answered question (the number of participants answering the question is listed above each question)

<sup>b</sup>part of acceptability definition

<sup>c</sup>Higher scores (max 100) indicate higher perceived level of preparation for testing[39]

patient reported feeling ‘very anxious’, no patients reported *increased* anxiety after using the guide, and 54% of patients felt the guide prepared them ‘a great deal’ or ‘quite a bit’ to make a better decision on mammography.

## Discussion

In acceptability testing, 45 women ages  $\geq 75$  with history of breast cancer and with strong mammography intentions and their oncology clinicians found an information guide on whether or not to continue mammography acceptable and clear. Overall, 89% of patients and 94% of clinicians stated that they would recommend the guide to others. Patients and clinicians also found the guide reasonable in length and suitable in content. Patients reported no increased anxiety after using the guide, and clinicians were enthusiastic to have the guide available for in-clinic use.

The high mammography utilization observed is consistent with prior observations [10], underscoring the importance of providing support and education to clinicians and patients in this context, likely through *longitudinal* discussions. Although five clinicians in our study stated they had intended to recommend discontinuing mammography before the visits, only one recommended discontinuation in the post-visit survey, perhaps due to strong patient preferences elicited during visits (though we did not ask why recommendations changed). Another important contributing factor is that 71% of patients in acceptability testing were ages 75–79, an age range where some will have > 10-year life expectancy and will be appropriately recommended to continue mammography [9]. Even when the timing is appropriate for

discontinuation, stopping mammograms in survivors may be challenging because of worry related to one’s personal cancer history and the often ingrained, perceived benefits of mammograms, without tools to adequately improve patients’ understanding of the harms of testing.

It is thus not surprising that a one-time intervention with a patient guide may not be sufficient in itself to impact mammography decisions. Instead, this may require repeated discussions over time with engaged clinicians, including primary care clinicians, ideally starting a few years ahead of when discontinuation of mammography will be considered. The patient guide and clinician-facing expert consensus guidelines[9] were developed with this in mind, with the goal to provide reassuring information that promotes informed decision-making, all in the context of one’s life expectancy, preferences, and underlying risk for new cancers. In clinical testing, when the guide *was* utilized, clinicians reported it was useful in these discussions. However, future testing of a patient guide will include alternative approaches to conveying this information to patients to better accommodate time constraints in clinic.

This high utilization of mammography among older breast cancer survivors in our study also confirms the clinician feedback received during our expert consensus guideline development [9], where focus group clinicians acknowledged the prevailing, habitual continuation of mammograms and difficulties incorporating conversations about life expectancy [9], consistent with the infrequent conversations reported in our study. Interestingly, although nine patients recalled discussing life expectancy, eighteen clinician surveys reported addressing this topic during the visit. Moreover, while 70% of oncology clinicians’ responses indicated



**Table 3** Post-visit clinician survey responses by patient visit ( $N=41$  surveys among 19 clinicians)

Question/responses by patient visit	Post-visit survey response (No. of surveys, % total surveys) <sup>a</sup>
What did you recommend in terms of mammograms for this patient?	$N=41$
Continue having mammograms	22 (54)
Get another one but consider stopping after that	4 (10)
It is the patient's choice	9 (22)
To not get one now but consider later	2 (5)
To stop getting mammograms	1 (2)
Other (continue until age 80, then stop [ $n=2$ ]; do mammograms as needed [ $n=1$ ])	3 (7)
Before the visit, what did you think you would recommend?	$N=40$
Continue having mammograms	17 (43)
Get another one but consider stopping after that	9 (23)
It is the patient's choice	7 (18)
To not get one now but consider later	1 (3)
To stop getting mammograms	5 (13)
I didn't think I would discuss mammograms	0 (0)
Other ( $n=1$ ; "patient came in with concerns for a breast nodule")	1 (3)
Did you discuss the pros of mammograms?	$N=41$
Yes	29 (71)
Did you discuss the cons of mammograms?	$N=41$
Yes	29 (71)
Did you discuss the patient's individualized risk of in-breast pre-invasive or invasive cancer events?	$N=41$
Yes	28 (68)
Did you discuss life expectancy?	$N=41$
Yes	18 (44)
If yes to discussing life expectancy, how did this go? Check <u>any</u> that apply:	$N=18$ from 'yes' above
Helpful to patient	12 (67)
Helpful to me	12 (67)
It was uncomfortable	0 (0)
Made decision-making easier for mammogram	10 (56)
Made decision-making harder for mammogram	0 (0)
Neutral effect	2 (11)
Other ("it was uncomfortable for the patient, not for me")	1 (6)
If no to discussing life expectancy above ( $n=23$ ), why not? Check all that apply:	
It didn't come up	15 (65)
I was uncomfortable talking about it	1 (4)
Patient did not want to discuss	0 (0)
Patient was anxious	3 (13)
Patient healthy so I didn't think it was important	4 (17)
I didn't have time	1 (4)
I didn't think it was important for this discussion	2 (9)
How did the guide affect the length of the visit with the patient?	$N=41$
Made visit a lot longer	1 (2)
Made visit a little longer, no effect on time, made visit a little shorter	30 (78)
I didn't use it	9 (22)
Other	1 (2)

<sup>a</sup>Among those who answered the question. The number of surveys from clinicians answering the question is listed above in each question

they reviewed the downsides of mammography, only 29% of patients perceived this topic was discussed, highlighting differing visit perceptions for clinicians and patients; future study could include observation of discussions to assess for shared decision-making.

To our knowledge, the “Are Mammograms Still Right for Me?” guide is the *first* resource for older breast cancer survivors to facilitate shared decision-making on mammography. Together with the clinician-facing guidelines and talking points [9], these materials provide much-needed, multi-faceted support for patients and their clinicians, including multidisciplinary physicians and advanced practice providers, that informs decisions rather than reflexively and indefinitely promoting mammograms. Based on the constructive feedback we received from acceptability testing, we revised the guide to include a more numerically balanced list of the benefits and harms of mammography, citations for the approximations for in-breast cancer events, and more reassuring text that physical exams and diagnostic evaluations will continue even if routine mammography is discontinued (Supplemental File S1).

We recognize several study limitations. Our study was limited in size and did not include a control population, non-English speaking patients, or a sufficiently diverse sample with regard to race, ethnicity, and socio-demographic factors. In addition, we did not mandate use of the guide or evaluate life expectancy and could not guarantee that the timing for mammography discussions was appropriate. Also, we included only oncology clinicians; we plan to include primary care clinicians in future evaluations and disseminations of the guide. Despite these limitations, clinicians rated the guide favorably and we obtained important initial implementation experience, all providing preliminary results for use of the guide in clinical practice.

Our results for acceptability will inform larger-scale studies that better engage diverse patient populations across various clinical settings and test the implementation of the patient guide through a multi-level, shared decision-making intervention that incorporates longitudinal patient-, clinician-, and practice-facing elements. This guide has the potential to enhance clinical practice by facilitating individualized decision-making for surveillance mammography among older breast cancer survivors but will require further study in larger, diverse practice settings and populations, and in particular, those with more limited life expectancy who are in most need of discussions on discontinuation of testing. The ultimate goal of this work is to further assess impact, standardize practice, and disseminate these novel resources to the growing number of older patients (and their clinicians) who are in urgent need of tailored approaches to survivorship care. Offering multi-layered support to pragmatically individualize mammography with a reassuring and informative approach has the potential to facilitate

de-implementation of routine mammography when it is unlikely to provide benefit and may cause harm.

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**Author contributions** All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Rachel Freedman, Anna Revette, Nancy Keating, and Mara Schonberg. The first draft of the manuscript was written by Rachel Freedman and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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**Data availability** The datasets generated during and/or analyzed during the current study are not publicly available due to patient privacy and the limitations stipulated in patient consent.

## Declarations

**Conflict of interest** Nancy U. Lin reports institutional research funding from Genentech, Merck, Pfizer, Seattle Genetics, AstraZeneca, Zion Pharmaceuticals, and Olema Pharmaceuticals; consultant/advisory board work for Pfizer, Puma, Seattle Genetics, Daiichi Sankyo, AstraZeneca, Prelude Therapeutics, Denali Therapeutics, Olema Pharmaceuticals, Aleta BioPharma, Affinia Therapeutics, Voyager Therapeutics, and Artera, Inc.; royalties from UpToDate; and stock or other ownership interests in Artera Inc. (a startup with no current value, but options only valued at <5% and <\$50,000 will be provided at a later date). The remaining authors declare that they have no conflicts of interest.

**Ethical approval** This study was performed in line with the principles of the Declaration of Helsinki and was approved by the DFCI Office of Human Research. Informed consent was obtained from all individual participants included in the study.

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

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