Breast Cancer Research

BRIEF REPORT

Open Access

Impact of an online decision support tool for ductal carcinoma in situ (DCIS) using a pre-post design (AFT-25)

Elissa M. Ozanne[1*], Kellyn Maves[2], Angela C. Tramontano[3], Thomas Lynch[4], Alastair Thompson[5], Ann Partridge[6], Elizabeth Frank[7], Deborah Collyar[7], Desiree Basila[7], Donna Pinto[7], Terry Hyslop[8], Marc D. Ryser[9], Shoshana Rosenberg[10], E. Shelley Hwang[11] and Rinaa S. Punglia[12]

Abstract

Background The heterogeneous biology of ductal carcinoma in situ (DCIS), as well as the variable outcomes, in the setting of numerous treatment options have led to prognostic uncertainty. Consequently, making treatment decisions is challenging and necessitates involved communication between patient and provider about the risks and benefits. We developed and investigated an interactive decision support tool (DST) designed to improve communication of treatment options and related long-term risks for individuals diagnosed with DCIS.

Findings The DST was developed for use by individuals aged > 40 years with DCIS and is based on a disease simulation model that integrates empirical data and clinical characteristics to predict patient-specific impacts of six DCIS treatment choices. Personalized risk predictions for each treatment option were communicated using icon arrays and percentages for each outcome. Users of the DST were asked before and after interacting with the DST about: (1) awareness of DCIS treatment options, (2) willingness to consider these options, (3) knowledge of risks associated with DCIS, and (4) helpfulness of the DST. Data were collected from January 2019 to April 2022. Users' median estimated risk of dying from DCIS in 10 years decreased from 9% pre-tool to 3% post-tool ($p < 0.0001$). 76% (n = 101/132) found the tool helpful.

Conclusions Information about DCIS treatment options and related risk predictions was effectively communicated, and a large majority participants found the DST to be helpful. Successfully informing patients about their treatment options and how their individual risks affect those options is a critical step in the decision-making process.

Clinicaltrials.gov Identifier NCT02926911.

Keywords Ductal carcinoma in situ, Breast cancer, Decision making, Decision support tool

*Correspondence:
Elissa M. Ozanne
elissa.ozanne@hsc.utah.edu
Full list of author information is available at the end of the article

Background/Introduction

Historically, the heterogeneous biology of breast ductal carcinoma in situ (DCIS), the limited knowledge regarding its disease course, and numerous treatment options, have limited the ability of clinicians to provide clear risk estimates of DCIS progression to invasive disease [1,2]. This prognostic uncertainty leaves DCIS patients with difficult treatment decisions that necessitate significant communication between patient and provider about the risks and benefits involved with treatment choices. We developed and investigated an interactive decision support tool (DST) to support communication of treatment options and long-term risks for individuals diagnosed with DCIS [3,4]

Methods

Using a pre-post study design, we evaluated the impact of a DST on decision making outcomes. The DST is based on a disease simulation model [5-7] that uses age at diagnosis and DCIS grade to predict patient-specific clinical impacts of six different treatment choices: (1) lumpectomy, (2) lumpectomy with radiation therapy, (3) lumpectomy with endocrine therapy, (4) lumpectomy with radiation and endocrine therapy, (5) mastectomy with or without reconstruction, and (6) bilateral mastectomy with or without reconstruction. Using this model, we designed a decision aid for clinicians that enabled a visual and numeric comparison across treatment strategies [3]. In collaboration with patient advocates and patient partners, this clinician-facing tool was subsequently adapted into an online patient-facing DST presented in this paper [4].

The DST was implemented through the website www.DCISoptions.org in collaboration with the COMET (Comparison of Operating to Monitoring, with or without Endocrine Therapy) study, a randomized trial of surgery versus active surveillance for low-risk DCIS. Users of the site were asked to provide age and DCIS grade, to access personalized information about predicted clinical impacts related to specific treatment choices. Patients were then asked to select one or more of the six treatment options for which they wished to have outcome information. General information for each treatment option, including active surveillance, was also provided in descriptive terms. Personalized 10-year risk predictions, including (1) subsequent development of DCIS or invasive breast cancer in the same breast, (2) the risk of dying from causes other than breast cancer, and (3) the risk of dying from invasive breast cancer, were communicated for each treatment using icon arrays (Fig. 1A-B).

While engaging with the website, site participants were asked to complete two surveys, one prior to interacting with the DST and one after. The survey assessed (1) impact of the DST on awareness of treatment options for DCIS, (2) impact of the DST on willingness to consider these options, (3) impact of the DST on knowledge of recurrence/mortality risks associated with DCIS, and (4) how helpful the DST was to them ("How helpful or not

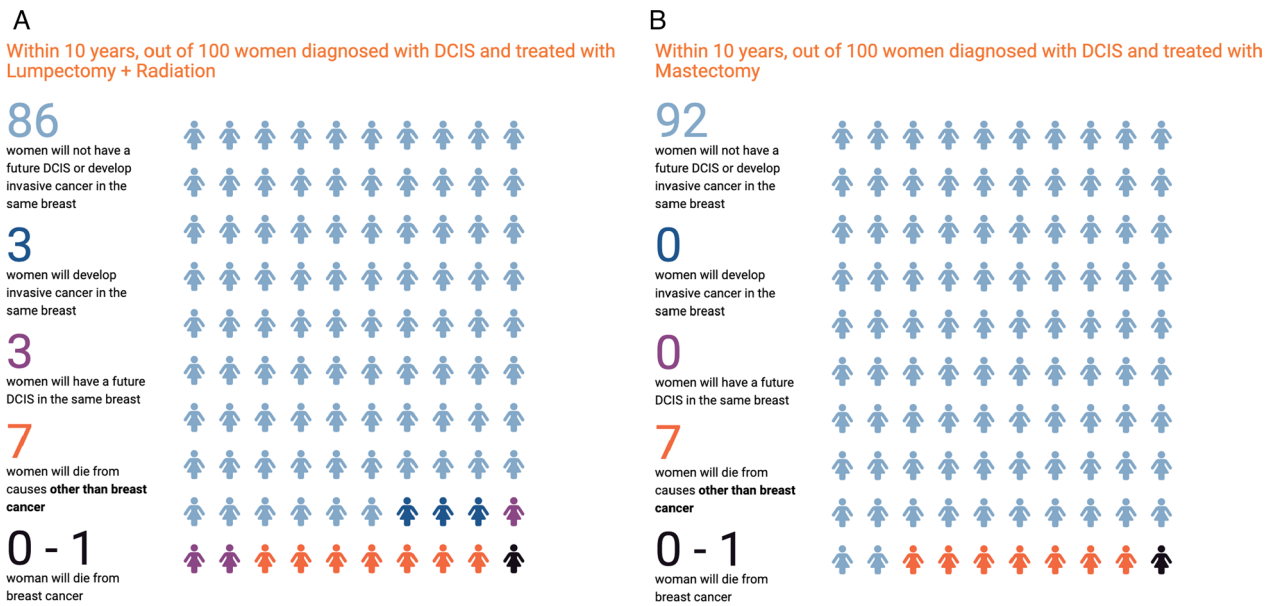

Fig. 1 **A** Outcomes Icon Array after Lumpectomy + Radiation. Example predicted patient specific 10 year outcomes for a 55 year old user with 'low or intermediate grade' DCIS who chooses treatment with 'lumpectomy + radiation'. **B** Outcomes Icon Array after Mastectomy. Example predicted patient specific 10 year outcomes for a 55 year old user with 'low or intermediate grade' DCIS who chooses treatment with 'mastectomy'

helpful was this decision tool in making a treatment decision for DCIS?").

Participants were those who visited the COMET website and engaged with the online DST and associated surveys. This protocol is approved by Quorum Centralized Institutional Review Board (dated July 11, 2018).

Statistical Analysis

We used chi-square tests to compare the distribution of age group (40–49, 50–59, 60 + years) and DCIS grade among patients who completed both the pre- and post-tool survey and those who only completed the pre-tool survey. Median age was compared using the Wilcoxon-Mann–Whitney test.

We focused on the cohort that answered both surveys to analyze potential differences in responses between the pre- and post-tool survey. The McNemar test was used to compare percentage distributions and the paired t-test was used to compare mean responses for questions using the Likert scale. We used the Wilcoxon signed rank test to compare median changes from pre- to post-tool survey. All statistical analyses were performed using SAS software, version 9.4 (SAS Institute, Inc., Cary, NC). Statistical significance was defined as $P < 0.05$ in a two-sided test. Data quality was ensured by review of data the study chairperson following Alliance policies.

Results

Data were collected from January 2019 to April 2022. As of April 19, 2022, there were 976 unique participants of the DST; 831 (85%) of these individuals completed the pre-tool survey and 145 (15%) completed both the pre- and post-tool survey. The median age of the DST participants was 54.0 years (15.0 years interquartile range [IQR]). Seventy-three percent of the participants indicated they had low/intermediate grade DCIS, while 19% indicated they had had high grade DCIS. There were no statistically significant differences in age group or DCIS grade between individuals who completed the pre-tool survey only and those who completed both the pre- and post-tool survey; the difference in median age between the two groups was statistically significant (p-value: 0.03) (see Table 1). Among participants who submitted both the pre- and post-tool survey, the average time spent on the DST was 10 min (13.4 min standard deviation [SD)] and the median time spent was 6 min (7 min IQR).

Participant awareness of each treatment option before use of the DST was high, with over 90% of individuals indicating awareness of the treatment options, except active surveillance (85.2%) and bilateral mastectomy (84.3%). This awareness did not change significantly after use of the tool for treatment options other than active surveillance. The percentage of participants with awareness of active surveillance increased from 85.2% pre- to 96.5% post-tool survey ($p = 0.004$). Use of the DST did not significantly alter participants' likelihood to consider the available treatment options.

Table 1 User demographics

	All users (N = 976)	Users with pre-tool survey only (N = 831)	Users with pre- & post-tool survey (N = 145)	P value
Age				
Mean (SD)	54.4 (9.8)	54.1 (9.8)	56.0 (9.8)	0.03
Median (IQR)	54 (15.0)	54 (15.0)	57 (16.0)	0.03
Min, Max	40, 80	40, 80	40, 79	
*Missing	118 (12.1%)	116 (14.0%)	2 (01.4%)	
Age Group				
40–49	315 (36.7%)	271 (37.9%)	44 (30.8%)	0.21
50–59	259 (30.2%)	215 (30.1%)	44 (30.8%)	
60 +	284 (33.1%)	229 (32.0%)	55 (38.5%)	
Grade				
Don't Know	69 (8.0%)	55 (7.7%)	14 (9.8%)	0.32
1	628 (73.2%)	520 (72.7%)	108 (75.5%)	
2	161 (18.8%)	140 (19.6%)	21 (14.7%)	
*Missing	118 (12.1%)	116 (14.0%)	2 (1.4%)	

* Missing not included in % for grade; chi sq test

Among participants who completed both the pre- and post-tool surveys, the DST was found to have effectively improved participants' prediction of the chance of dying from DCIS. The percentage of participants who correctly identified that the chance of dying from DCIS is 'Very Low' increased from 60.0% pre- to 73.8% post-tool survey ($p < 0.0001$) (Fig. 2A). Correspondingly, the median estimated risk of dying from DCIS in 10 years decreased from 9% pre-tool to 3% post-tool ($p < 0.0001$) (Fig. 2B). There were no statistically significant differences in the pre- and post-tool median estimated 10-year risk responses of individuals in different age groups. Finally, 76% (n = 101/132) found the tool helpful.

Discussion

Communication about DCIS treatment must consider challenging factors like patient age, overall health, cancer grade and size, individual values/preferences, and care goals to achieve patient-centered decision-making. Many patients overestimate the risk of dying from breast cancer after a DCIS diagnosis [8,9]. Inadequate communication about DCIS prognosis and treatment options has been shown to impact patients' treatment decisions, increase anxiety, and lower quality of life [10,11]. Insufficient communication with patients may also be associated with overtreatment of the disease [12].

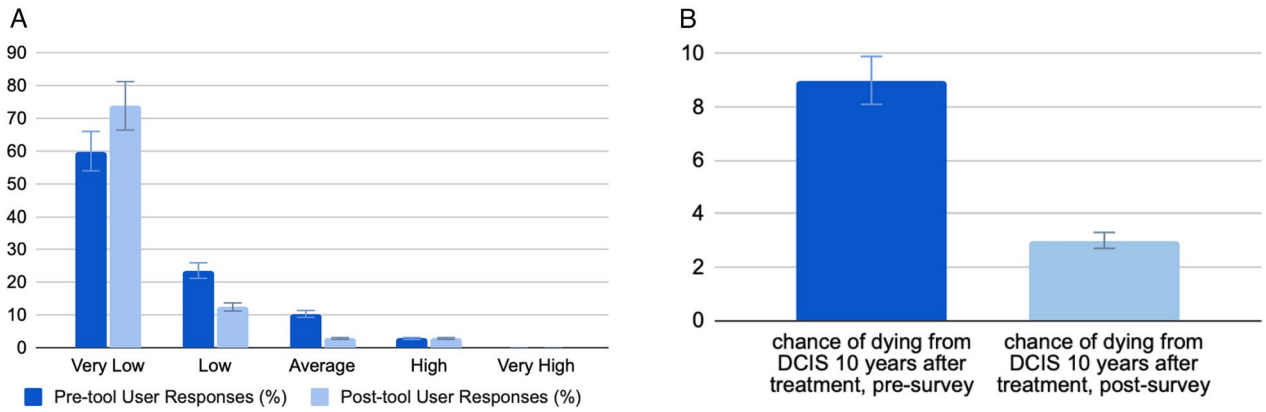

Fig. 2 **A** Pre- and Post-tool responses to chance of dying from DCIS. **B** Pre- and Post-tool responses to chance of dying from DCIS 10 years after treatment

This study demonstrated that an online DST effectively communicated information about DCIS treatment options and related risk predictions. Active surveillance awareness increased significantly, and most patients found the DST to be helpful. The DST also significantly improved knowledge about chances of dying from DCIS, helping to anchor decision making to a key outcome. The ability of our DST to successfully inform patients about their treatment options and how their individual risks affect those options may lead to improved decision making and patient outcomes.

This study has several limitations. Although patients were typically directed to our DST through the COMET study website, we were unable to verify that the pre- and post-tool surveys were only completed by patients with a new DCIS diagnosis. Additionally, we did not capture data related to health literacy/numeracy, digital access, and financial status, all of which may have impacted a participant's access to the DST, and their likelihood of completing the surveys. Finally, it is possible that those who chose to respond to the post-tool survey were better informed, possibly biasing the results. Future research will include a clinical trial of the tool aimed toward assessing the impact of the DST on patient-provider communication during clinical visits, and its impact on treatment decision-making.

Abbreviations

DCIS	Ductal carcinoma in situ
DST	Decision support tool
COMET	Comparison of operating to monitoring, with or without endocrine therapy study
IQR	Interquartile range
SD	Standard deviation

Acknowledgements
All statements are solely those of the authors and do not necessarily represent the views of PCORI, its Board of Governors or Methodology Committee.

Author contributions
E.O. R.P. and K.M. wrote the main manuscript text and A.T. completed the analyses. All authors reviewed the manuscript.

Funding
This work was supported through a Patient-Centered Outcomes Research Institute (PCORI) Award (PCS-1505–30497) and the Alliance Foundation Trials, LLC.

Availability of data and materials
The data are available from the authors upon reasonable request.

Declarations

Ethics approval and consent to participate
This protocol is approved by Quorum Centralized Institutional Review Board (dated July 11, 2018).

Consent for publication
Not Applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]Department of Population Health Sciences, School of Medicine, University of Utah, Population Health Sciences, 295 Chipeta Way Rm 1N512, Salt Lake City, UT 84108, USA. [2]University of Utah, Salt Lake City, UT, USA. [3]Division of Population Sciences, Dana-Farber/Partners Cancer Care Institute, Boston, MA, USA. [4]Department of Surgery, Duke University Medical Center, Durham, NC, USA. [5]Baylor College of Medicine, Houston, TX, USA. [6]Dana-Farber Cancer Institute, Boston, MA, USA. [7]Alliance Foundation Trials, LLC, Boston, MA, USA. [8]Thomas Jefferson University, Philadelphia, PA, USA. [9]Department of Population Health Sciences, Duke University Medical Center, Durham, NC, USA. [10]Department of Population Health Sciences, Weill Cornell Medicine, New York, NY, USA. [11]Duke University Medical Center, Durham, NC, USA. [12]Department of Radiation Oncology, Dana-Farber/Partners Cancer Care, Boston, MA, USA.

Received: 25 May 2024 Accepted: 7 September 2024
Published online: 17 September 2024

References

1. Allegra CJ, Aberle DR, Ganschow P, et al. NIH state-of-the-science conference statement: diagnosis and management of ductal carcinoma in situ (DCIS). NIH Consens State Sci Statements. 2009;26(2):1–27.
2. Ryser MD, Hendrix LH, Worni M, Liu Y, Hyslop T, Hwang ES. Incidence of ductal carcinoma *in situ* in the United States, 2000–2014. Cancer Epidemiol Biomarkers Prev. 2019;28(8):1316–23. https://doi.org/10.1158/1055-9965.EPI-18-1262.
3. Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer Statistics, 2021 [published correction appears in CA Cancer J Clin. 2021 Jul;71(4):359]. *CA Cancer J Clin*. 2021;71(1):7–33. https://doi.org/10.3322/caac.21654
4. Soeteman DI, Stout NK, Ozanne EM, et al. Modeling the effectiveness of initial management strategies for ductal carcinoma in situ. J Natl Cancer Inst. 2013;105(11):774–81. https://doi.org/10.1093/jnci/djt096.
5. Ozanne EM, Schneider KH, Soeteman D, et al. onlineDeCISion.org: a web-based decision aid for DCIS treatment. Breast Cancer Res Treat. 2015;154(1):181–90. https://doi.org/10.1007/s10549-015-3605-y.
6. Ozanne EM, Soeteman DI, Frank ES, et al. Commentary: Creating a patient-centered decision aid for ductal carcinoma in situ. Breast J. 2020;26(7):1498–9. https://doi.org/10.1111/tbj.13779.
7. Bluman LG, Borstelmann NA, Rimer BK, Iglehart JD, Winer EP. Knowledge, satisfaction, and perceived cancer risk among women diagnosed with ductal carcinoma in situ. J Womens Health Gend Based Med. 2001;10(6):589–98. https://doi.org/10.1089/15246090152543175.
8. Davey C, White V, Warne C, Kitchen P, Villanueva E, Erbas B. Understanding a ductal carcinoma in situ diagnosis: patient views and surgeon descriptions. Eur J Cancer Care (Engl). 2011;20(6):776–84. https://doi.org/10.1111/j.1365-2354.2011.01265.x.
9. Omer ZB, Hwang ES, Esserman LJ, Howe R, Ozanne EM. Impact of ductal carcinoma in situ terminology on patient treatment preferences. JAMA Intern Med. 2013;173(19):1830–1. https://doi.org/10.1001/jamainternmed.2013.8405.
10. Partridge A, Adloff K, Blood E, et al. Risk perceptions and psychosocial outcomes of women with ductal carcinoma in situ: longitudinal results from a cohort study. J Natl Cancer Inst. 2008;100(4):243–51. https://doi.org/10.1093/jnci/djn010.
11. Hawley ST, Janz NK, Griffith KA, et al. Recurrence risk perception and quality of life following treatment of breast cancer. Breast Cancer Res Treat. 2017;161(3):557–65. https://doi.org/10.1007/s10549-016-4082-7.
12. Kim C, Liang L, Wright FC, et al. Interventions are needed to support patient-provider decision-making for DCIS: a scoping review. Breast Cancer Res Treat. 2018;168(3):579–92. https://doi.org/10.1007/s10549-017-4613-x.

Publisher's Note