Acceptability and Usability of iPrevent®, a Web-Based Tool for Assessment and Management of Breast Cancer Risk.

By

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ABSTRACT

Purpose: iPrevent® estimates breast cancer (BC) risk and provides tailored risk management information. This study assessed the usability and acceptability of the iPrevent® prototype. **Methods:** Clinicians were eligible if they worked in primary care, breast surgical or genetics clinics. Female patients were eligible if aged 18-70 years with no personal cancer history. Clinicians were first familiarised with iPrevent® using hypothetical paper-based cases, then actor scenarios and then subsequently used iPrevent® with their patients. Clinicians and patients completed the System Usability Scale (SUS) and an Acceptability questionnaire 2 weeks after using iPrevent®, and patients also completed measures of BC worry, anxiety, risk perception and knowledge pre- and 2 weeks post-iPrevent®. Data were summarised using descriptive statistics. **Results:** 20 clinicians and 43 patients participated. Usability was above average (SUS score >68) for most clinicians (68%) and patients (76%). Most clinicians (89%) and patients (89%) reported that the amount of information provided by iPrevent® was about right and most (95% and 98% respectively) would recommend iPrevent® to others, although 10 (53%) clinicians and 10 (27%) patients said it was too long. Exploratory analyses suggested iPrevent® could improve risk perception, decrease frequency of breast cancer worry and enhance breast cancer prevention knowledge without changing state anxiety. **Conclusions:** The iPrevent® prototype demonstrated good usability and acceptability. Because concerns about length could be a barrier to implementation, data entry has been abbreviated in the publically available version of iPrevent® which can be found at www.petermac.org/iprevent

Keywords:

Decision support, breast cancer, BRCA1, BRCA2, risk, prevention, screening, usability, implementation

Abbreviations:

BC	Breast cancer
SUS	System Usability Score
BRCA1	BReast CAncer susceptibility gene 1
BRCA2	BReast CAncer susceptibility gene 2
BS	Breast surgeon(s)
GC	Genetics clinician(s)
PCP	Primary care physician(s)
IBIS	International Breast Cancer Intervention Study
BOADICEA	Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm
PMCC	Peter MacCallum Cancer Centre

INTRODUCTION

Breast cancer (BC) is a major public health problem, accounting for over 1.67 million cases worldwide each year [1]. In addition to population-based educational and public health policy interventions to minimise exposure to modifiable BC risk factors and optimise cancer screening, identifying women at increased risk and implementing risk-stratified, evidence-based prevention and intensified screening strategies for them is a priority [2]. Healthcare providers often have difficulty assessing and communicating BC risk, and the absolute benefits and disadvantages of risk management interventions such as risk-reducing medication, surgery and cancer screening [3-4].

Several tools exist to estimate BC risk based on personal risk factors, but none provides risk-adapted, individually-tailored, risk management information [5]. iPrevent® was designed to help women and their healthcare providers, including primary care physicians (PCP), breast surgeons (BS) and genetics clinicians (GC), to assess and manage BC risk collaboratively [6]. It integrates BC risk estimation, using either the International Breast Cancer Intervention Study (IBIS) model or the Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm (BOADICEA) model (as appropriate to the woman's risk factors), with tailored risk management information [7-9].

iPrevent® users are first given a qualitative risk estimate, according to Cancer Australia definitions: average or slightly above average risk (<1.5 times population risk at that age), moderately increased risk (1.5 to 3 times population risk), or high risk (>3 times population risk) [10]. The woman can then choose to see her risk information displayed as a percentage, a pictogram and/or a graph. Women are also provided with a menu of risk management strategies appropriate to their risk category, based on Australian National Guidelines [11], with optional more detailed information about each strategy, including estimates of the absolute (rather than relative) risk reductions for each medical and surgical intervention, and tailored lifestyle advice.

The aims of this pilot study of patients and their clinicians were to assess the iPrevent® prototype with regard to its clinical usability, and the acceptability of its content and layout, and to identify

potential barriers to its implementation. Exploratory aims included assessing its potential impact on patient risk perception, anxiety, BC worry, and BC prevention knowledge.

METHODS

Study Setting

Stage 1 piloting was undertaken by the researchers with women who had previously received risk assessment and risk management advice at the Peter MacCallum Cancer Centre (PMCC) Breast and Ovarian Cancer Risk Management Clinic [12]. Stage 2 piloting involved PCP, BS and GC in public hospital and private primary care, breast and genetics clinics and their patients. Patients and clinicians were unselected for level of BC risk or prior experience with BC risk assessment.

Eligibility Criteria

Eligible patients were women aged 18 to 70 years with no personal history of cancer and who provided written informed consent. Patients with previous risk-reducing bilateral mastectomy or major medical co-morbidities were excluded. Eligible clinicians were PCP, BS, or GC with a workplace computer with web access. English proficiency was required for all participants.

This study was approved by the Human Research and Ethics Committees of the University of Melbourne and the PMCC.

Stage 1: Piloting on Patients With Prior Risk Assessment

Ten patients were enrolled from the PMCC Breast and Ovarian Cancer Risk Management Clinic. Baseline information on age, education, computer literacy [13], and both the perceived BC risk category (average, somewhat increased or substantially increased) [10] and perceived percentage lifetime BC risk was collected. Patients then used iPrevent® supervised by a research assistant (PW/ ES). The time for data input was recorded. Patients were emailed the report in Portable Document Format (PDF). Two weeks after using iPrevent®, they completed a questionnaire

assessing usability and acceptability of iPrevent®, knowledge and psychosocial outcomes. They could review the emailed iPrevent® output while answering these questions.

System Usability Scale (SUS)

This 10-item instrument [14] uses a 5-point Likert rating scale from 'strongly agree' to 'strongly disagree' to measure product usability. It is applicable to small samples [15] and correlates well with other subjective measures of usability [16-17]. Final scores range from 0-100 and a SUS score of >68 is considered above average.

iPrevent® Acceptability Questionnaire

This 9-item measure, adapted from a previous evaluation of a decision aid [18] uses Likert scales to elicit perceptions of the length, clarity, balance and usefulness of iPrevent®.

Breast Cancer Risk Perception

This single item adapted from a study measuring impact of genetic counselling, asked patients their BC risk category: 'average', 'somewhat increased', or 'substantially increased' [19]. Women were classified as under-estimators, accurate estimators, or over-estimators, based on comparison with the risk estimated by iPrevent®.

BC Worry Scale

The Lerman BC worry scale is a 3-item scale. Higher scores indicate increased frequency and impact of worry [20].

Spielberger State-Trait Anxiety Inventory (STAI)

The short form STAI (6-items) measures state anxiety; higher scores indicate higher anxiety [21].

BC Prevention Knowledge

Sixteen items assessing knowledge regarding BC (11 items), risk-reducing medication (3 items), and risk-reducing mastectomy (2 items) were adapted from published knowledge measures (see

Supplementary table 1) [22-23]. Although every woman was asked to answer all questions, the number of responses scored for each participant was dependent on the iPrevent®-determined risk category. All average risk women and those moderate risk women aged < 35 years were assessed only on BC knowledge questions. Older moderate risk women were also assessed on risk-reducing medication questions. High risk women were assessed on all 16 questions. The proportion of correct responses was calculated.

Semi-structured interviews were also conducted in Stage 1 (data will be reported separately).

Stage 2: Piloting with Clinicians and Their Patients

Twenty clinicians were recruited from previous focus groups [3-4] (5 BS and 3 PCP), or by email invitation from KAP (1 BS and 6 GC) or the PMCC PCP liaison officer (5 PCP).

Clinicians first underwent a 'familiarisation' session. Supervised by a research assistant (PW / ES), clinicians first entered data into iPrevent® on three hypothetical patients (high, moderate and average risk) and reviewed the iPrevent® output information. On the same day, clinicians then conducted 2 mock consultations with female actors: one at high risk, the other moderate risk. Patient (actor) information was pre-entered into iPrevent® and clinicians were asked to use the iPrevent® output with the actors as they might in a clinical consultation.

Clinicians were then asked to invite 3 eligible patients from their practice (either during patient appointments or by telephone prior) during the following 3 months, to participate by entering their information into iPrevent® prior to a consultation and attending an appointment with the clinician to receive the 'output'. Patients were provided a printout of their iPrevent® output by email. Clinicians recorded the amount of time spent using iPrevent®.

All patients were asked to complete the same pre- and post-iPrevent® assessments as in Stage 1. Two weeks after recruitment of 3 patients (or 3 months after familiarisation, if full patient recruitment did not occur), clinicians completed the SUS and Acceptability questionnaires.

Semi-structured interviews of patients and clinicians were also conducted in Stage 2, and data will be reported elsewhere.

Statistical Analyses

All statistical analyses were performed in R 3.2.3 (R Core Team (2015)).

The planned sample size of 20 clinicians and 60 patients was based on pragmatic estimates of the numbers it was considered possible to recruit over the available time period. The purpose of the study was to assess the acceptability and usability of iPrevent® for clinicians and patients and not to test hypotheses, therefore descriptive statistics were used to summarise the data (mean, median and range for continuous variables, counts and percentages for categorical variables). Patient and clinician data were analysed separately. A pairwise t-test was used to assess whether the STAI score changed from pre- to post-iPrevent® assessment.

RESULTS

The study recruited 20 clinicians, and 43 patients (10 for Stage 1 and 33 for Stage 2). Clinicians only recruited 33 of the planned 60 patients (planned 3 per clinician). BS (6) recruited 16 of a planned 18 patients, GC (6) recruited 14 of a planned 18 patients (1 GC moved overseas during the study and was thus unable to recruit her 3 planned patients) and PCP (8) recruited only 3 of a planned 28 patients.

Participant Characteristics

Patient characteristics are shown in Table 1. Median age was 38 years (range 21 to 56 years), most had university education (74%) and were at moderate risk for BC (51%). Clinician characteristics are shown in Table 2. Their median age was 47 years (range 28 to 66 years), most were either PCP (40%) or BS (30%) and all but 3 (15%) were female. The majority used computers often and rated themselves as having good computer skills.

iPrevent® Data Entry and Consultation Times

Patients took a median of 15 (range 5-60) minutes to enter their risk factor data. The median time taken for clinician consultations in which iPrevent® data was discussed, was 20 (range 5-45) minutes.

iPrevent® Usability and Acceptability

SUS responses are summarised in Figure 1. Overall 76% of patients and 68% of clinicians rated iPrevent® usability as above average (SUS score >68). Table 3 shows that iPrevent® was generally acceptable to study participants. Eighty-nine percent of clinicians and patients reported that the amount of information provided by iPrevent® was “about right”. Ten clinicians (53%) and ten patients (27%) reported that iPrevent® was too long. Only 1 patient and 1 clinician reported the information was not clear, and that they would ‘probably not’ recommend iPrevent® to others.

Exploratory Endpoints

Of 35 patients who completed relevant questions before iPrevent®, 40% (n=14) correctly indicated their BC risk category, but 51% (n=18) overestimated and 9% (n=3) underestimated their BC risk category. Post-iPrevent®, 86% (n=30) accurately estimated their risk category, although 11% (n=4) and 3% (n=1) continued to overestimate or underestimate risk, respectively.

After iPrevent, 19% (n=7) of women reported worrying about BC ‘often’ or ‘all the time’, compared to 26% (n=11) before. Regarding impact of BC worry on mood and daily activities, 69% reported a low score (1 to 1.5 out of 4) pre-iPrevent®. After iPrevent®, 25% of patients reported less impact, 47% reported no change, and 28% reported more impact.

The mean short form STAI score (maximum 24) pre-iPrevent® was 11.3 (SD=3.8) and it was 10.9 (SD=3.7) post-iPrevent® (median difference of 1 (95% CI -0.5 to 2), p=0.140).

Overall BC prevention knowledge improved for all risk groups. (Supplementary Table 2)

DISCUSSION

This pilot study of the iPrevent® prototype has found good usability and acceptability without evidence of an adverse impact on anxiety or BC worry. The observation that the 8 PCP recruited only 3 patients between them in the required 3-month period suggests that implementation of iPrevent® into primary care might be substantially more challenging than implementation into the specialist setting, where recruitment of patients was much higher. Another interpretation is that the study requirements (e.g. obtaining written informed consent) were onerous especially for PCP in busy practices and thus the low recruitment by PCP in this study might not reflect uptake of iPrevent® in routine practice. However, as earlier focus groups had highlighted that PCP generally do not see BC risk assessment and management as being in their domain, iPrevent® might be able to contribute to overcoming provider unfamiliarity and lack of confidence for this group of clinicians [3].

The prototype was considered too long by a majority of clinicians and some patients, indicating another potential barrier to implementation. Patients took a median of 15 minutes, and up to 60 minutes to enter their risk factor data and the subsequent median time taken for the clinician consultation using the iPrevent® output was 20 minutes. To address this issue, we have now incorporated changes to streamline data entry for family history. This study also highlighted the need for patients to be able to enter their data into iPrevent® at home prior to a consultation.

iPrevent® may improve BC risk perception given an additional 46% of patients accurately estimated their BC risk category after using iPrevent®. As higher perceived risk of BC is associated with considering medical prevention and risk-reducing surgery among high-risk women [24-26], iPrevent® could become a potential behaviour-modifying tool. While this pilot study provides no information about uptake of risk management strategies after using iPrevent®, this issue will be an important endpoint for future larger studies. Other studies have found that women who have access to more thorough information from genetic counsellors, combined with support to make decisions, have

higher uptake of risk reduction methods [27-29] so it is hypothesised that iPrevent® might have a similar impact.

Use of iPrevent® did not appear to increase patient worry or anxiety, consistent with the literature which has found that decreased anxiety and better psychological outcomes are associated with improved accuracy of perceived risk [24, 30-31].

Use of iPrevent® seemed to improve BC knowledge, a recognised critical first step in helping individuals understand screening options, weigh potential benefits and risks for risk-reducing measures, and make informed decisions [32-34]. In addition, 89% of patients indicated that some or most of the information contained in iPrevent® was new to them (Table 3).

This pilot had several limitations. Firstly, the sample was small and the study did not achieve its target patient recruitment. The majority (74%) of patients were young and highly educated so the acceptability and usability of iPrevent® might differ in the general community where computer literacy might be lower. Similarly, clinicians who chose to participate could have been more highly engaged with BC risk assessment and risk management than non-participant clinicians. Finally, only short-term outcomes were measured and the impact on long-term satisfaction and uptake of BC risk-reducing measures could not be determined.

As a result of this study, enhancements have been made to iPrevent® with the aim of further increasing acceptability and usability. iPrevent® is freely available for use by women and their clinicians at www. petermac.org/iprevent

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INFORMED CONSENT

Informed consent was obtained from all individual participants included in the study.

ETHICAL APPROVAL

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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