



# Multimedia Patient Education for Cancer Genetic Testing

Grant Number: R44CA79349-03

## Abbreviated Abstract

Proposed is the development of a patient education CD ROM for individuals considering BRCA1/2 testing. BRCA1/2 are the two major genes associated with an increased risk of hereditary breast and ovarian cancer. The program is intended to supplement the patient education information provided by genetic counselors, medical geneticists, other physicians, nurses, patient educators and advocates. Helping patients understand this complex topic and make informed and appropriate decisions about testing minimizes the potential for negative emotional and social consequences. The use of CD ROM technology presents material in an engaging, interactive format with visually enhanced explanations. Patients can access this information at their own pace, maximizing privacy and minimizing any sense of pressure. A Web site was developed in conjunction with the program that will allow users to get current news and program updates in advances in BRCA1/2 testing and the field of cancer genetics. Phase I addressed development of the structure and content for the intervention program. Phase II will entail production of a completed version of the program, a clinical field trial to test the efficacy and safety of the program, and an evaluation of end user satisfaction.

## Primary Investigator

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Dr. Simon Budman, Inflexxion President and CEO, is a clinical psychologist and on the faculty of the Harvard Medical School. Prior to starting Inflexxion, he was the Director of Mental Health Research and the Director of Mental Health Training at the Harvard Community Health Plan, a pioneering HMO affiliated with the Harvard Medical School. He also served as the Associate Director of the Institute for Health Research at the Harvard School of Public Health. Among his many significant awards and honors, he received the Career Contributions Award from the Massachusetts Psychological Association in 1993 and in 2000 he received one of the highest awards offered by the American Psychological Association for Distinguished Contributions to Professional Knowledge and the prestigious Psyche Award from the Nicholas and Dorothy Cummings Foundation. Inflexxion is a leader in the use of multimedia technology for prevention, screening and treatment in behavioral health. Many of the health products developed by Inflexxion are scientifically tested and are supported by grants from the National Institutes of Health..

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## Research Team & Affiliations

Inflexxion staff: Simon Budman, Ph.D. Principal Investigator; Jonas Bromberg, Ph.D. Co-principal Investigator; Evelyn Corsini, M.S.W. Project Manager; Anne Marie Rakowski, M.S. Project Manager; Julie Simmons, B.S. Research Coordinator; Diana Rancourt, B.S. Research Coordinator; Ellen Balber, Editor.

## Total Budget

\$779,315

## Research Objectives

Aim 1: Completion of the PREDICT CD-ROM and completion of the comparison website to supplement PREDICT.

Aim 2: To test two hypotheses, assess the safety of the PREDICT program, to assess consumer satisfaction with the PREDICT program, and to assess professional satisfaction with PREDICT as a clinical tool.

## Theory/Hypothesis

1. Individuals exposed to the program will increase knowledge about inherited breast and ovarian cancer and the BRCA1/2 testing process including potential risks and benefits.
2. Increase satisfaction with their decision about pursuing BRCA1/2 testing in comparison to a control group.

## Experimental Design

There were 233 people involved in the study who were randomized into an experimental group and a control group. The experimental group received education in the form of the PREDICT CD-ROM and the control group received education in the form of an NCI booklet. Participants were assessed at two time points, baseline and 1 month. At baseline participants received the BRCA1&2 and testing, perception of benefits and limitations of testing, cancer anxiety, current decision about testing. At the 1 month follow up participants received the BRCA1&2, perception of benefits and limitations of testing, cancer anxiety, current decision about testing, and satisfaction with decision.

## Final Sample Size & Study Demographics

233 people participated in this study. 98 percent of the participants were female. The mean age was 44.58 years and 89 percent of the participants were white. 62 percent of the participants were married and 38 percent had a college degree. 90 percent of the participants completed the study.

## Data Collection Methods

Participants were assessed at two time points, baseline and 1 month. At baseline participants received the BRCA1&2 and testing, Perception of benefits and limitations of testing, Cancer anxiety, Current decision about testing. At the 1 month follow up participants received the BRCA1&2, Perception of

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benefits and limitations of testing, Cancer anxiety, Current decision about testing, and Satisfaction with decision.

## Outcome Measures

1. Demographic questionnaire
2. Knowledge about Inherited Breast- Ovarian Cancer and BRCA1/2 testing.
3. Perceptions of the Benefits, Limitations and Risks of BRCA1/2.
4. Satisfaction with Decision scale.
5. Cancer-Related Anxiety and Helplessness scale.
6. Consumer Satisfaction Scales.

## Evaluation Methods

## Research Results

All participants had a high baseline knowledge and improved significantly. In addition the experimental group had a more balanced perception of benefits and limitation of testing, due primarily to their seeing a decrease in the benefits. There was no significant change in cancer anxiety in either group. Fifty two percent of participants in the control group remained undecided one month after intervention versus thirty seven percent in the experimental group, showing that the PREDICT was a useful decision aid. In addition participants using PREDICT felt more adequately informed about the issues important to their decision about testing. There were no significant differences between the clinical and pre clinical groups.

## Barriers & Solutions

No major problems encountered

## Product(s) Developed from This Research

### **PREDICT (Predisposition Risk Education in Cancer Testing)**

The program is intended to supplement the patient education information provided by genetic counselors, medical geneticists, physicians, nurses, patient educators and advocates, in order to help patients understand make informed and appropriate decisions about testing and minimize the potential for negative emotional and social consequences.