Psychological impact of providing women with personalized ten-year breast cancer risk estimates

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Why risk stratified screening?

Benefits
(fewer deaths, lower stage at detection, chemotherapy avoided, mastectomy avoided)

Harms
(false positive test results, overdiagnosis, radiation-induced cancers, opportunity costs, anxiety)
Now possible to estimate breast cancer risk

- **Self-reported information** (family history of cancer, age, age at menarche, age at first full term pregnancy, HRT use, BMI, etc)
- **Breast density** (assessed from mammograms)
- **Genetic factors** (BRCA1 and BRCA2 gene mutations, + currently 200 known genetic variants that can increase the risk of breast cancer: Single Nucleotide Polymorphisms [SNPs])
- **Predicting Risk of Cancer At Screening (PROCAS)**
Invitation to screening

~70% attend

Invitation to fill in a risk factor form

~47% enter

Mammography + informed consent

~94% want to know risk

Risk estimation
Tyrer-Cuzick +Density (+SNPs)

Mammography + informed consent

~94% want to know risk

Consultation to discuss prevention options

Moderate risk (10.3%)
Average risk (59.3%)
Below average risk (27.2%)
What is the psychological impact of receiving breast cancer risk estimates?

• To assess the psychological impact of receiving breast cancer risk estimates, based on: (a) the Tyrer–Cuzick (T-C) algorithm including breast density or (b) T-C including breast density plus SNPs, versus (c) comparison women awaiting results.

• Need to communicate risk to women in PROCAS between 2-5 years after risk estimated
Present study

• PPI input suggested verbal labels more helpful than precise numerical estimates (10 years)
  – High risk (8% and over)
  – Moderate risk (5-7.9%)
  – Average risk (2-4.9%)
  – Below average risk (up to 1.9%)

• Letters sent out – some also received questionnaires
Design/Sample/Analysis

• Natural experiment
  – Test group (TC, TC+SNPs, control)
  – Result group (moderate, average, below average)
• 2066 questionnaires sent/ 765 returned (37%)
• At least 200 sent to each group (59<n<110 returned)
• Analysis (ANCOVA – control for confounders)
  – (1) TC v TC+SNPs
  – (2) Intervention (TC and TC+SNPs v controls)
Results: Comparative risk perception

- **TC+SNPs**
  - Moderate: 4.0
  - Average: 4.5
  - Below average: 2.0

- **TC**
  - Moderate: 4.2
  - Average: 3.0
  - Below average: 1.5

- **Controls**
  - Moderate: 3.0
  - Average: 3.5
  - Below average: 2.5
Results: State anxiety (STAI short form)
Results: Cancer worry (Lerman)
Results: Satisfaction with information
Understanding and intentions to change behaviour

- Understanding generally good: “which of the following best describes what your test result means”
- No consistent effects on intentions to change 6 behaviours
So what do we know now?

• No evidence of major harms (anxiety or cancer worry)
• Good satisfaction with information
• Understanding generally good
• Not a barrier to examining feasibility of implementing in routine screening.
• PROCAS2 study

Thank you
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Communicating test results: Developing materials

- Developed leaflet
- PPI input
- Drafted text
- “Think aloud” interviews + open-ended interviews
- Iterative revisions
## Results: not well matched groups

<table>
<thead>
<tr>
<th></th>
<th>TC+SNPs (n=271)</th>
<th>TC only (n=197)</th>
<th>Controls (n=297)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>62.9 (6.9)</td>
<td>54.3 (4.2)</td>
<td>52.4 (2.9)</td>
</tr>
<tr>
<td><strong>First mammography</strong></td>
<td>30.3%</td>
<td>81.2%</td>
<td>93.9%</td>
</tr>
<tr>
<td><strong>BMI</strong></td>
<td>27.4 (5.6)</td>
<td>27.0 (4.8)</td>
<td>26.1 (4.6)</td>
</tr>
<tr>
<td><strong>IMD</strong></td>
<td>5.3 (2.7)</td>
<td>5.8 (3.0)</td>
<td>6.3 (2.9)</td>
</tr>
</tbody>
</table>
| **Area**             | **Trafford (36%)**  
                      | **Withington (33%)**  
                      | Manchester (11%)  
                      | Oldham (11%)  
                      | Salford (9%)  
                      | Tameside (0%)  | **Trafford (26%)**  
                      | Withington (9%)  
                      | Manchester (8%)  
                      | Oldham (18%)  
                      | Salford (12%)  
                      | **Tameside (27%)**  | Trafford (19%)  
                      | Withington (4%)  
                      | Manchester (7%)  
                      | Oldham (14%)  
                      | Salford (10%)  
                      | **Tameside (46%)**  |
| **Days from test to** | 1132 (77)       | 992 (81)        | 939 (67)        
| **result**           |                 |                 |                 |
Where next? PROCAS-2 study

- Feasibility of automated risk estimation as routine part of NHS Breast Screening Programme
- Developing care pathways and refining materials, with input of low SES and BME women, and other key stakeholders
- Automating risk estimation (online)
- Establish major benefits and harms
- Including likely cost effectiveness
- Implementation meetings