Are there psychological harms of providing women with personalized ten-year breast cancer risk estimates?

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Why communicate ten-year breast cancer risk estimates?

- NICE recommends that women at high risk of breast cancer should be offered: (a) additional mammography and (b) chemoprevention
- BUT...few women are identified as being at high risk
- There are good predictive tests for future breast cancer risk, specifically Tyrer-Cuzick test (with info about breast density) and SNPs
- Should women be offered this test?
Harms/benefits of communicating ten-year breast cancer risk estimates

- Anxiety
- Worry about cancer
- Satisfied with information sent
- Accurate risk perceptions
- Understand risk information
- Changes in intentions to change behaviour linked to cancer risk
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)

High-risk (3.2%)

Consultation to discuss prevention options

Moderate risk (10.3%)

Average risk (59.3%)

Below average risk (27.2%)
Present study

• Women in PROCAS study given risk information 2-5 years after risk estimated
• Co-designed letters and leaflets to communicate personal risk
  – Moderate risk (5-7.9% ten-year risk)
  – Average risk (2-4.9% ten-year risk)
  – Below average risk (up to 1.9% ten-year risk)
• Letters sent out – some also sent 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: 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>
<tr>
<td><strong>Area</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trafford</td>
<td></td>
<td>Trafford</td>
<td>Trafford</td>
</tr>
<tr>
<td>Withington</td>
<td>(36%)</td>
<td>(26%)</td>
<td>(19%)</td>
</tr>
<tr>
<td>Manchester</td>
<td>(33%)</td>
<td>Withington</td>
<td>Trafford</td>
</tr>
<tr>
<td>Oldham</td>
<td>(11%)</td>
<td>(9%)</td>
<td>(4%)</td>
</tr>
<tr>
<td>Salford</td>
<td>(9%)</td>
<td>Oldham</td>
<td>Oldham</td>
</tr>
<tr>
<td>Tameside</td>
<td>(0%)</td>
<td>Salford</td>
<td>(14%)</td>
</tr>
<tr>
<td><strong>Days from test to result</strong></td>
<td>1132 (77)</td>
<td>992 (81)</td>
<td>939 (67)</td>
</tr>
</tbody>
</table>
Results: State anxiety (STAI short form)
Results: Cancer worry (Lerman)
Results: Satisfaction with information
Results: Comparative risk perception
Understanding and intentions to change behaviour

- Understanding generally good, apart from:
- 36/461 “this result does not tell me anything about my future risk”
- 7/461 “I do not know what my test result means”
- No effects on intentions to change behaviour
So what do we know now?

• No evidence of major harms (anxiety or cancer worry)
• Good satisfaction with information
• Understanding generally good, but some misunderstandings apparent (esp for TC+SNPs)
• Study limitations – long duration testing to results
• Unbalanced groups
Where next?

• PROCAS2 study
• Feasibility of automated risk estimation as part of NHS-Breast Screening Programme
• Will refine materials and develop care pathways, with input of low SES and ethnic minority women, and other key stakeholders
• Automate risk estimation (online)
• Establish likely benefits and harms
• Implementation meetings
Thank you
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